FACILITATORS AND INHIBITORS OF INDEPENDENT SELF-MANAGEMENT OF ADOLESCENTS WITH TYPE 1 DIABETES

by

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As members of the Dissertation Committee, we certify that we have read the dissertation prepared by Rita Elizabeth Jean Meadows, titled Facilitators and Inhibitors of Independent Self-Management of Adolescents with Type 1 Diabetes and recommend that it be accepted as fulfilling the dissertation requirement for the Degree of Doctor of Philosophy.

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ABSTRACT

Purpose: The purpose of this qualitative descriptive study was to identify the facilitators and inhibitors of independent self-management of T1DM by adolescents, to elicit their perceptions of behaviors required for independent self-management and, to identify resources used by this population to support independent self-management.

Background: Type 1 diabetes (T1DM) is one of the leading chronic diseases in childhood. In 2009 an estimated 166,984 U.S. children < 20 years old had a diagnosis of T1DM. Based on a 21% increase in the rate of T1DM between 2001-2009, it is projected that 600,000 children and adolescents will have T1DM by 2050. Adolescents with T1DM will eventually join the 1.25 million adults independently managing their T1DM. A smooth transition from dependent to independent self-management is imperative to prevent harmful long-term outcomes of the disease.

Methods: Eleven adolescents- Five males and six females, carrying a T1DM diagnoses for at least one year participated in focus group interviews for this qualitative description study. The focus group interviews were transcribed verbatim and analyzed using qualitative content analysis.

Results: Three domains emerged from an overarching theme, “Sorry, I have diabetes...It shaped me into who I am”: Self-management behavior skills required for the adolescent with T1DM during transition from dependent to independent T1DM self-management; Facilitators of everyday participation in self-management behaviors for adolescents with T1DM; and Inhibitors of everyday participation in self-management behaviors for adolescents with T1DM. The behaviors of independent self-management of adolescents with T1DM included preparation &

knowledge, responsibility, and self-advocacy. Facilitators of everyday participation in self-management behaviors for adolescents with T1DM included Community influences, and Navigating the healthcare system. Community influences included the Family, Peers and Extra-community of the adolescent with T1DM. Three subcategories fell under Navigating the healthcare system included *"Not making a big deal about it" "Technology allows more freedom"* and the *Interpersonal relationships with healthcare providers*. Three categories reflected the third domain, *Inhibitors of everyday participation in self-management behaviors for adolescents with T1DM*. The three categories include *Lack of self-accountability, Lack of community support,* and *Difficulty navigating the healthcare system*. The first category, *Lack of self-accountability*, branched into four subcategories: *Demands of T1DM self-management, Embarrassment, Blaming,* and *Lack of self-responsibility*. Four subcategories also evolved from the second category, *Lack of community support*: *Lack of family support, Peers who "don't understand,"* and *Conflicts with school nurses*. The third category, *Difficulty navigating the healthcare system*, branched into two subcategories; *Poor interpersonal relationships*, and *Gatekeepers*.

Conclusions: Transitional programs must cater to the unique psychological, developmental, and disease-specific needs of the adolescent with T1DM to improve competence in self-management skills. Effective transition programs will need to focus on the psychological, behavioral, neurological, neurocognitive, and hormonal influences on T1DM independent self-management.

CHAPTER 1: INTRODUCTION

Problem Statement

Adolescents with type 1 diabetes (T1DM) must begin the gradual transition from dependent self-management provided by their parents to assuming independent T1DM self-management. Adolescents with T1DM are among the 19.4% of children and adolescents under 21 years old in the United States with special health needs, as reported by the 2016 National Survey of Children's Health – which includes children that "have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally" (Mattson & Kuo, 2018; Lemly, Weitzman, & O'Hare, 2013; McPherson, Arango, Fox, Lauver, McManus, Pollack, Cooley, & McAllister, 2013). During 2009-2010, only 40% of adolescents with special health care needs, including those with T1DM in the United States between the ages of 12-18 years achieved the national core outcomes for successful transition to independent disease self-management within the adult healthcare system (Little, Odiaga, & Minutti, 2016; McManus et al., 2013). These statistics were unchanged since the prior 2005-2006 survey, indicating the need for more successful independent self-management transitional programs for the adolescent with T1DM (McManus et al., 2013).

Adolescents with T1DM most commonly transfer from pediatric to adult healthcare, which requires independent self-management, between the ages of 18-25 years. (Lyons, Becker, & Helgeson, 2014). The preparation for this transfer from dependency on parents for T1DM management to independent self-management should begin in early adolescence and accomplished at least one year before transfer to adult healthcare (American Diabetes

Association [ADA], 2018). Consequences of poor transition to independent self-management may include poor glycemic control, permanent adverse microvascular and macrovascular health outcomes and strained interpersonal relationships with parents, peers and healthcare providers. (Bomba, Herrmann-Garitz, Schmidt, Schmidt, & Thyen, 2017; Castensøe-Seidenfaden, Teilmann, Kensing, Hommel, & Olsen et al., 2017; Beal, Riddle, Kichler, Duncan, Houchen et al., 2016; Campbell, Biggs, Aldiss, O'Neill, Clowes et al., 2016; Ersig, Tsalikian, Coffey, & Williams, 2016; Hagger, Hendrieckx, Sturt, Skinner, & Speight, 2016; Babler & Strickland, 2015; Chu, Maslow, von Isenberg, & Chung, 2015; Egan, Corrigan, & Shurpin, 2015; White, O'Connell, & Cameron, 2015; Sheehan, While, & Coyne, 2014; Helgeson, Reynolds, Siminerio, Becker, & Escobar, 2014; Hilliard, Perlus, Clark, Haynie, & Plotnick et al., 2014; Rollo, Salardi, Ciavarella, Forlani, Scipione et al., 2014; Lyons et al., 2014; Sonneveld, Strating, van Staa, & Nieboer 2013; Garvey, Markowitz, & Laffel, 2012; Hanna, 2012).

There have a number of studies conducted that have investigated facilitators and inhibitors of independent self-management of adolescents with T1DM (Farrell, Fernandez, Salamonson, Griffiths, & Holmes-Walker, 2018; Kapellen, Müther, Schwandt, Grulich-Henn, Schenk et al., 2018; Bomba et al., 2017; Carlsen, Skrivarhaug, Thue, Cooper, & Goransson et al., 2017; Hansen & Jensen, 2017; Sawicki, Garvey, Toomey, Williams, Hargraves et al., 2017; Wong, 2017; Babler & Strickland, 2016; Beal et al., 2016; Campbell et al., 2016; Castensøe-Seidenfaden et al., 2016; Ersig et al., 2016; Hagger et al., 2016; Joley, 2016; Little et al., 2016; Los, Ulrich, Guttman-Bauman, 2016; Quinn, Ambrosino, Doyle, Weyman, Tamborlane et al., 2016; Schmidt, Herrmann-Garitz, Bomba, & Thyen, 2016; Babler, & Strickland, 2015; Chu et al., 2015; Egan et al., 2015; Joley, 2015; Mistry, Van Blyderveen, Punthakee, & Grant, 2015;

Polfuss, Babler, Bush & Sawin, 2015; Raymond, 2015; White et al. , 2015; Fernandez, 2014; Helgeson et al., 2014; Hilliard et al., 2014; Lyons et al., 2014; Maiorino, Bellastella, Petrizzo, Improta, Brancario et al., 2014; Rollo et al., 2014; Sheehan et al., 2014; Sullivan-Bolyai, Bova, Johnson, Cullen, Jaffarian et al., 2014; Wiebe, Chow, Palmer, Butner, & Butler, 2014), and transitional programs (Schmidt et al., 2016; Egan et al., 2015; Mistry, et al., 2015; Polfuss et al., 2015), yet transitional needs of the adolescent with T1DM are still not being met (Sawicki et al., 2017; Little et al., 2016; Lemly et al., 2013; Mcmanus et al., 2013). Current transitional concepts reported in the literature include the ability of the adolescent with T1DM to 1) access educational, healthcare and psychosocial resources, 2) master the specific skills needed for glucose monitoring and management, 3) become independent with insulin and medication administration, 4) manage hypoglycemia and sick days, and 5) understand the impact of nutrition on glycemic control (Sheehan et al., 2014; Garvey et al., 2012). Despite research and transitional programs, there is insufficient knowledge to explain why adolescents with T1DM continue to be unsuccessful with transitioning from dependent to independent self-management. Further research that explores and identifies the facilitators and inhibitors of transition from dependent to independent self-management of the adolescent with T1DM, from their perspective, is needed to inform transitional interventions.

Purpose

The purpose of this qualitative descriptive study was to 1) identify the facilitators and inhibitors of independent self-management of T1DM by adolescents, 2) to elicit their perceptions of behaviors required for independent self-management and, 3) to identify resources used by this population to support independent self-management.

Research Questions

1. What are the self-management behavior skills required for the adolescent with T1DM during transition from dependent to independent T1DM self-management?
2. What facilitates everyday participation in self-management behaviors for adolescents with T1DM?
3. What are the barriers to participating in everyday self-management behaviors for adolescents with T1DM?

Background

T1DM is one of the most prevalent childhood diseases in the United States (Pettitt, Talton, Dabelea, Divers, Imperatore et al., 2014; ADA, 2018; Lee, Lo, Lee, Chen, & Wang 2015). According to the most recent data between 2003 and 2012, among the 1.25 million people in the United States with T1DM, children under the age of 20 years account for approximately 193,000 cases. Between 2011-2012, 17,900 youths were diagnosed with T1DM in the United States (ADA, 2018). Of all cases of T1DM between 2003-2012, adolescents were found to be the most rapidly growing population, with a reported rate of 1.8% (Mayer-Davis, Lawrence, Dabelea, Divers, Isom et al., 2017).

Among individuals with T1DM, adolescents are at highest risk for death by acute complications of T1DM, highlighting the seriousness and urgency for nursing interventions to alleviate the burdens of T1DM for this vulnerable population (Lachin, Bebu, Nathan, Zinman, Brillon et al. 2016; Mameli, Ben Nasr, Fiorina, Scaramuzza, & Zuccotti, 2015). The diagnosis of T1DM is associated with reduced life expectancy and increased risk for microvascular and macrovascular disease (Carlsen et al., 2017; Lachin et al., 2016; Lee et al., 2015; Nathan, for the

DCCT/EDIC Research Group, 2014.) Macrovascular disease, autonomic neuropathy, and renal dysfunction increase the risk of heart attack and stroke by ten times and any cardiovascular disease by 30% (Lachin et al., 2016; Nathan et al., 2014). Intensive insulin therapy can significantly reduce microvascular and macrovascular complications of T1DM (Carlsen et al., 2017; Lachin et al., 2016; Nathan et al., 2014).

The economic burden of managing T1DM is vexing on the adolescent with T1DM and their families, but also has a significant impact on national economies (Johnson, Eiser, Young, Brierley & Heller, 2013; Shi, Stevens, Lebrun, Faed, & Tsai, 2008). The average healthcare costs in the United States is estimated to increase by 2.3 with the diagnosis of diabetes and accounts for one in every four dollars of U.S. health care expenditures (ADA, 2018). Uncertainties related to healthcare insurance status, and the rising costs of healthcare further complicate the transition to independent self-management for the adolescent with T1DM.

T1DM: Adolescent Physiological Considerations for Independent Self-Management

Type 1 diabetes is a metabolic disorder characterized by alteration in glucose metabolism due to the autoimmune destruction of pancreatic beta cells responsible for the production of insulin. Insulin release and regulation in the body is dependent on the proper functioning of the endocrine system, inflammatory mechanisms, and the central nervous system, the processes involved in adolescent growth and development and puberty that uniquely impact the adolescent with T1DM (Daruna, 2012). The absence of the normal physiological processes of insulin production during adolescence is challenging to healthy physical growth and development.

During adolescence, activation of growth hormone, cortisol, prolactin (PRL), gonadal steroids, and insulin-like growth factor cause rapid physical growth and increased insulin production (Wright & Kutcher, 2016; Daruna, 2012; Brown, Strasburger, Coupey, Rogers, & Braverman et al., 2005). Increased insulin secretion during adolescence synergistically stimulates increased physical growth (Wright & Kutcher, 2016; Daruna, 2012; Brown et al., 2005). The adolescent with T1DM requires increased exogenous insulin to meet the demands of physical growth and maintain glycemic balance. Concomitantly there is increased activity of proinflammatory cytokines- proteins that regulate inflammation and further diminish the effect of insulin on the body resulting in insulin resistance (Wright & Kutcher, 2016; Daruna, 2012; Brown et al., 2005). Because of insulin resistance, the management needs of the child with T1DM significantly changes during adolescence.

Glycemic excursions in adolescents with T1DM cause changes in brain growth and metabolic demands within the brain, which affect brain development (Cato & Hershey, 2016). Current research associates the length of diabetes diagnosis, the age at onset of T1DM, increased exposure to hypoglycemia and hyperglycemia, and the exposure to diabetic ketoacidosis (DKA) with long-term cognitive impairment, learning disabilities and lower academic achievement (Cato & Hershey, 2016).

Independently of puberty and hormonal changes in adolescence, the brain undergoes physical changes that affect behavior (Salmela-Aro, 2011; Wright & Kutcher, 2016). The areas of the brain responsible for impulse control, judgment, and organization experience the most considerable changes during middle adolescence (Grant, McMahon, Duffy, & Taylor, 2011; Salmela-Aro, 2011).

Significant differences in brain growth have been found between children and adults with T1DM versus those without T1DM (Fox, Hershey, Mauras, Arbeláez, Tamborlane et al., 2018; Mazaika, Weinzimer, Mauras, Buckingham, White et al. 2015; Marzelli, Mazaika, Barnea-Goraly, Hershey, Tsalikian et al., 2014). This includes alterations in gray and white matter growth and ventricular volumes in the medial and lateral frontal regions of the brain which are involved in executive, emotional, and social functioning (Fox et al., 2018; Mazaika et al., 2016; Marzelli et al., 2014). This is troublesome for the adolescent with T1DM attempting to independently manage their T1DM.

Neuroanatomical impairments of brain development that result from hyper and hypoglycemic excursions lead to cognitive deficits and psychological dysfunction (Marzelli et al., 2014). Earlier research identified differences in brain growth in those diagnosed with T1DM earlier in childhood, but current research found higher correlations between persistent hyperglycemia effects versus early exposure to hyperglycemic excursions and brain development (Marzelli et al., 2014). Recent studies of intensive insulin therapy were found to carry a three-fold risk for hypoglycemia without an association with cognitive deficits (Lachin, et al., 2016; Cenzig, Xing, Wong, Wolfsdorf, Haymond et al., 2013). Independent self-management treatment decision-making behaviors may be cognitively impacted by glycemic excursions.

Glycosylated hemoglobin (HgbA1C) is used to measure the percentage of glucose bound to red blood cells and is representative of metabolic control in individuals with T1DM. The HgbA1C target goal of <7.5% is only being met by 17% of adolescents with T1DM (ADA, 2018; Farrell et al., 2018; Little et al., 2016; Los et al., 2016). However, HgbA1C only

tells part of the story of glycemic management because it fails to reflect fluctuations in daily management skills (ADA, 2018; Farrell et al., 2018; Little et al., 2016; Los et al., 2016). The fluctuations in daily self-management skills are the preventable behaviors that may lead to poor glycemic control (ADA, 2018; Farrell et al., 2018; Little et al., 2016; Los et al., 2016).

Self-Management of T1DM

Self-management of T1DM during childhood and adolescence is an "active, daily, and flexible process in which youth and their parents share responsibility and decision-making for achieving disease control, health and well-being through a wide range of illness-related activity" (Schilling, Grey, & Knafl, 2002, p. 92). Antecedents of T1DM self-management include the individual, family, and social networks, the interventions required for disease management (i.e., blood glucose monitoring, taking insulin, maintaining proper nutrition and activity levels, and the nature of the illness) (Ahola & Groop, 2013). However, the empirical measurements of glycemic control are not solely reflective of self-management of T1DM (Schilling et al., 2002). For example, individuals with extreme fluctuations in glucose levels may have similar HgbA1C readings as one with consistent lower readings. However, the behaviors that contribute to the glycemic excursions in T1DM may increase the adolescent's risk for poor health outcomes.

The adolescent with T1DM must master over 600 self-management tasks to achieve independent self-management (Babler & Strickland, 2015). These tasks include physical tasks, emotional adjustments to disease, and disease-specific skills necessary for decision-making and problem-solving (Babler & Strickland, 2015). The treatment goals of T1DM self-management include insulin administration, nutrition therapy, exercise, sick-day management, psychosocial considerations, co-morbid autoimmune disease management, and screening for complications

and other co-morbid conditions (Radovick & Misra, 2018). Those with T1DM are dependent on insulin, proper nutrition, and psychological, educational, psychosocial and financial resources for disease management. The support and assistance of a multidisciplinary team of clinicians-pediatric endocrinologists, nurse practitioners, certified diabetes educators, nutritionists, social workers, and psychologists, is also needed to meet the goals of T1DM self-management (Radovick & Misra, 2018).

Independent vs. Dependent T1DM Self-Management

Children are reliant on parents who retain, until later in adolescence, the responsibility of dependent diabetes management. The adolescent with T1DM is expected to transition between dependent and independent diabetes management to prepare for an eventual and successful change to the adult healthcare environment. Therefore, adolescents with T1DM must eventually assume primary responsibility of accessing resources to maintain glycemic control and manage their own health (ADA, 2018).

Children and adolescents may be capable of performing self-management behaviors before they are ready for independent T1DM self-management (Schilling et al., 2002). Mastery of the tasks of self-management by the adolescent with T1DM coincides with the transition from dependent to independent self-management. The transition from dependent to independent self-management coincides with the achievement of the physical, psychological and psychosocial milestones of adolescent growth and development and puberty.

The processes, activities, and goals of self-management underlie the interdependent relationship between the adolescents and the healthcare system and the practice of transferring responsibility of T1DM management from parent to child (Schilling et al., 2002). As children

with T1DM learn the tasks of self-management such as dosing and administration of insulin and blood glucose monitoring, there is a shift from complete parental supervision of T1DM management tasks to a more collaborative relationship between the adolescent and parent (Castensøe-Seidenfaden et al., 2017). Adolescents with T1DM must eventually take on the full responsibility of managing their T1DM to achieve independent self-management (Castensøe-Seidenfaden et al., 2017). Severe health consequences, including death, can result from incomplete or inaccurate independent self-management of T1DM (Wasserman, Anderson, & Schwartz, 2017).

Independent self-management of T1DM is not absent of dependence. It requires a dependency on personal, community and societal resources. Independent self-management refers to the responsibilities of T1DM self-management and the supervision required for meeting self-management needs. Independent self-management is marked by both the ability to master the tasks of glycemic management and the development of decision making and problem-solving skills required to navigate the healthcare system, and access and utilize the resources needed for positive health outcomes (ADA, 2018; Castensøe-Seidenfaden et al., 2017). The adolescent with T1DM is expected to learn skills of independent self-management such as making medical appointments and navigating diabetes-related care costs to successfully transition from the pediatric to the adult healthcare setting (ADA, 2018).

Consequences of poor independent self-management behaviors influence metabolic control. Metabolic markers can be used as markers to reflect successful independent self-management. For example, the association between higher HgbA1C and decreased frequency of

blood glucose monitoring are indications of a poor transition to independent self-management (Rollo et al., 2014; Schilling et al., 2002).

Care Environment and Transitional Care

Management of type 1 diabetes (T1DM) is intrusive and complex and poses a significant challenge to the maturing adolescent (Wasserman et al., 2017; Lansing, Berg, Butner, & Wiebe, 2016). The adolescent with T1DM contends with a metabolic struggle between the hormonal changes of puberty and their disease process. While the adolescent with T1DM navigates through the stages of physical growth and development, the demands and consequences of disease management, such as glycemic excursions, alter their biophysical and psychological functioning (Colombini & Schivalocchi, 2013). Concomitantly, the adolescent begins a social transformation as their role in their community and society evolves. The psychological, psychosocial, and physiological forces confronting the adolescent with T1DM make achieving their developmental milestones difficult and influences, often negatively, T1DM disease management (Shi et al., 2008).

Recent guidelines highlight the need for increased research into the self-management skills, educational and psychosocial issues, and physical support of the adolescent with type 1 diabetes (T1DM) during their transition from dependent to independent self-management (ADA, 2018). Nursing interventions are needed to mediate inhibitors of and facilitate a smooth transition to independent self-management of the adolescent with T1DM to independent self-management and glycemic control. Nursing interventions must include thorough knowledge of 1) the relationship between T1DM and adolescent physical, psychological, and psychosocial growth and development and puberty, 2) the concepts of dependent vs. independent disease

management of the adolescent with T1DM, and 3) the facilitators and inhibitors of healthy transition of the adolescent with T1DM from dependent to independent self-management.

Transitional needs of the adolescent with T1DM include timing of transitional planning, the graduated transfer of diabetes management tasks to the adolescent from caregivers, the inclusion of youth in healthcare decisions and management of diabetes, and the preparation of teenagers for the adult care environment and communication guidance with adult providers (ADA, 2018; Little et al., 2016). A study of the inhibitors and facilitators to independent self-management among adolescents with T1DM as well as their perceptions of the required behaviors for independent self-management will inform future nursing interventions for a successful transition.

Theoretical Framework: Meleis' Transitions Theory

Afaf Meleis' transitions theory (Meleis, 2010) provided the theoretical framework for this research study (Figure 1). Transitions theory describes the relationships between the nature of human transitions, conditions, facilitators and inhibitors of transitions, patterns of response to transitions, and nursing therapeutics and transition interventions. The nursing metaparadigm is used to identify the interconnected nature of nursing, person, health, and environment within a theory. An explicit correlation exists between the nursing metaparadigm concepts and the propositions of transitions theory.

Meleis (2010) defines nursing as "the art and science of facilitating the transition of populations 'health and well-being" and "being concerned with the processes and the experiences where health and perceived well-being is the outcome." The main function of nursing is role supplementation (Meleis, 2010). Nursing, as the primary caregiver during a

transition, is concerned with the risk that transition places on a person and family (Meleis, 2010). The goal of nursing is to prevent risk, enhance well-being, maximize functioning and assist in mastering self-care activities (Meleis, 2010).

Meleis' transition theory and antecedent knowledge evolved from the sociological, nursing and educational background of Afaf Meleis (Meleis, 2010). Transition theory evolved in the 1960s from role theory (Meleis, 2010). Meleis adopted the definition of role from role theory, which identifies a person's role as a sociopsychological construct of the interactions of individuals within a social system (Meleis, 2010). Meleis' worldview was for a post-modernistic perspective (Meleis, 2010, p. 624). As a situation-specific theory focus developed, with the inclusion of society and community as influences in transition experiences of vulnerable populations, a feminist post-colonialism paradigm prevailed (Meleis, 2010, p. 620).

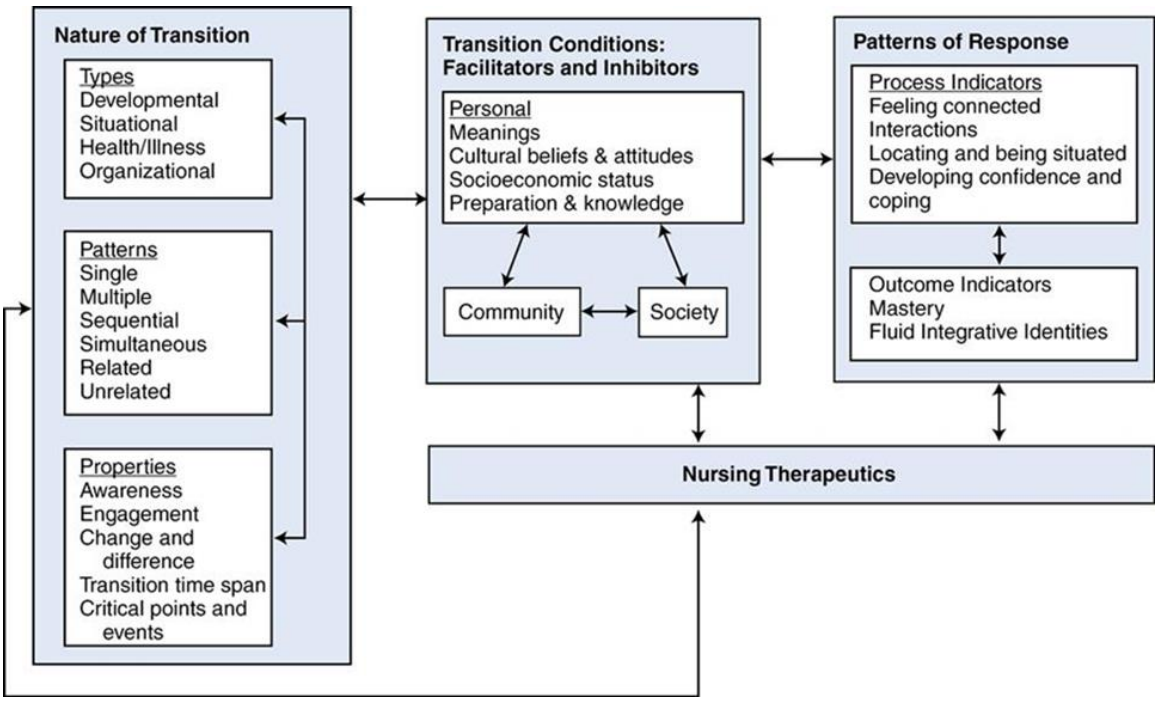


FIGURE 1. Afaf Meleis' middle range transitions theory. (Meleis, Sawyer, Im, Hilfinger Messias & Schumacher, 2000)

Nature of Transitions

In this study, the health-illness transition of the adolescent with T1DM was explored. Health-illness transitions are sudden or gradual changes between states of wellness and illness, which require a nursing focus on both the individual and the illness state (Meleis, 2010). However, this transition occurred within the context of the developmental transition of adolescence, which created a unique nature of transition; a health-illness-developmental transition.

The patterns of transition examined in this study included the gradual, sequential health-illness transitions of the adolescent with T1DM from dependent to independent self-management. The bidirectional influences between the health-illness transition of the adolescent with T1DM and developmental changes of adolescence further supported a proposed health-illness-developmental transition pattern.

Several interrelated properties of transition proposed in transition theory apply to the transition of the adolescent with T1DM to independent self-management. This study examined the properties of awareness and perception of the adolescent with T1DM in the process of transition to independent self-management and their engagement and degree of involvement in the transition process. The properties of role changes and differences in adolescent behaviors that result from the transition to independent self-management of T1DM, and the critical points and events that trigger the need for change were also examined (Meleis, 2010).

Transition Conditions: Facilitators and Inhibitors

Transition theory may be considered in relation to domain concepts of nursing therapeutics, environment, and client. Nursing interventions are viewed in relationship to

transitions, antecedents, and consequences and are dependent upon timing, patterns, and types of transitions and timing of intervention (Chick & Meleis, 2010). Adjustment to changes in the support offered by the environment surrounding the transition and the stability of the environment may influence the transition process (Chick & Meleis, 2010). Transitions are influenced not only by individual and environmental variables, but also the interplay between these variables (Chick & Meleis, 2010). Influential conditions of transition include meanings, expectations, level of knowledge and skill, the environment, level of planning, and emotional and physical well-being (Schumaker, 2010).

Insufficient knowledge and skill during transitions may influence health outcomes (Schumaker, 2010). For example, if the adolescent is not knowledgeable of the required T1DM self-management behaviors then independent self-management is not likely to be successful resulting in poor glycemic control. Resources within the environment that include social support, collaborations, and the wider sociocultural environment shape the transition process (Schumaker, 2010) which provides the rationale for exploring resources the adolescent uses to engage in independent T1DM self-management. Effective planning for a transition needs an understanding of the actual and potential needs during a transition to ensure a smooth process (Schumaker, 2010). Physical and psychosocial stressors as discussed previously may interfere with the adolescent's ability to assimilate new knowledge and achieve/maintain optimal glycemia during transitions (Schumaker, 2010).

Patterns of Response

Transition theory concepts and performance indices may be observed and explored through qualitative inquiry or quantitatively evaluated, measured, and statistically analyzed for

significance. Process indicators, behaviors of mastery and integrated role identities include the concepts of connectedness and situation in new roles, the interactions with the community and society following new role mastery, and the development of confidence and coping skills required for the performance of a new role (Meleis, 2010). Role mastery is measured by individual competence in knowledge, psychomotor skill, decision-making abilities and self-confidence (Schumaker, 2010). The resolution of distress in and restoration of disrupted relationships during the transitional process are indicators of healthy transitions (Schumaker, 2010).

Nursing Therapeutics

Transitions theory centralizes on the skilled, therapeutic nursing interventions required for smooth transitions (Meleis, 2010). Nursing transition interventions begin with an assessment of the readiness of the individual to transition and development of individual profiles that identify patterns within the transition experience (Schumaker, 2010). Nurses then help to prepare the individual for transition, providing education, preparing environments in which transition occurs and creating appropriate timetables for gradual adaptation to new roles and acquisition of skills (Schumaker, 2010). The final nursing therapeutic is role supplementation to facilitate transition (Schumaker, 2010).

Pragmatic adequacy of transitions theory is further supported by the education and special skill training required before application of theory in nursing practice, the application of the theory to real-world settings, and the feasibility of implementation of practice derived from the theory. The ability of the practitioner to legally implement and measure the effectiveness of theory-based nursing actions, the compatibility of the expectations of nursing practice with the

theory-based actions also supports the practical application of Transition theory in nursing practice. Further, the favorable outcomes that result from the theory may be compared to outcomes of the same situation without the application of the theory (Meleis, 2010).

Significance to Nursing

In 2002, the American Academy of Pediatrics (AAP), American Academy of Family Physicians, and the American College of Physicians (ACP) responded to the difficulties of a growing number of adolescents with unique health needs transitioning from pediatric to adult healthcare (Lemly et al., 2013; American Academy of Pediatrics (AAP), American Academy of Family Physicians, American College of Physicians, American Society of Internal Medicine, 2002). This group of experts developed transition guidelines for adolescents age 12 and older with special health needs from pediatric to adult healthcare (Lemly et al., 2013; AAP et al., 2002). The guidelines consist of the six core outcomes: 1) the development of transition policy, 2) enrollment of youth in a transition registry to monitor the preparation, 3) planning and outcomes of transition, 4) transition preparation, 5) transition planning, transitions and transfer of care, and 6) transition completion (Lemly et al., 2013).

Fundamental concepts of transitional needs identified in the literature have broadly focused on adolescents and young adults with T1DM in the process of transition to independent self-management. Deciphering the behavior of the adolescent with T1DM is complex. This study is significant to nursing because of the need to understand the process in which the adolescent with T1DM assumes independent self-management behaviors, adapts self-management behaviors in everyday life, and identifies the processes involved in the transition from dependent to independent self-management skills and behaviors (Chilton & Pires-Yfantouda, 2015). The

results of this study may inform nursing transition programs that assist adolescents with T1DM in the transition to independent self-management.

Summary

Adolescents are the future leaders, consumers, community members and society that will create, maintain and improve human life (Lerner, Boyd, Kiely, Napolitano, & Schmid, 2011). The adolescent with T1DM must organize and define experiences of disease management while navigating through normal growth and development. The adolescent with T1DM uses formal operational reasoning to reflect upon glycemic management. They must make logical inferences based on responses to management decisions and the development of hypotheses and rationales to care behaviors and outcomes (Newman & Newman, 2011). Cultural, educational and neurological factors impact the adolescent's ability for executive function (Newman & Newman, 2011). Healthy and delayed growth and development, the outcomes of the disease process and the skills required for management of T1DM can restrict the physical, emotional, social and psychological evolution of the adolescent with T1DM.

Conclusion

Adolescents in the United States with chronic health conditions do not receive standardized, quality transitional preparation (Sawicki et al., 2017). Current research on the success of transition planning programs meeting the needs of adolescents with T1DM has shown mixed results. The determinants of successful adolescent transition to independent self-management and descriptions of the processes and protocols of transition require further clarification through research to develop, monitor and evaluate transition programs (Chu et al., 2015; Sheehan et al., 2014).

CHAPTER 2: LITERATURE REVIEW

Introduction

The transition of the adolescent with T1DM to independent self-management co-occurs with the rapid physical, psychosocial and psychological development and the hormonal changes of puberty (Bomba et al., 2017; Ersig et al., 2016; Castensøe-Seidenfaden et al., 2016; Helgeson et al., 2014). Adolescents who are not adequately prepared for and assisted through the transition process are more vulnerable to poor health outcomes (Beal et al., 2016; Babler & Strickland, 2015; White et al., 2015). Development of transitional nursing interventions require better understanding of the transition conditions- the facilitators and inhibitors of transition of the adolescent with T1DM to independent self-management.

Review of the Literature

A literature review was conducted to identify the concept of transition related to adolescent T1DM self-management (Table 1) and to explore the facilitators and inhibitors of independent self-management of the adolescent with T1DM. A search was conducted on PubMed, PsychINFO, Embase, Google Scholar, and CINAHL using multiple MESH terms and Boolean phrases including, “transition,” “adolescent,” “diabetes mellitus, type 1,” “transition to adult care,” “insulin-dependent diabetes mellitus,” “self-management,” and “self-care.” Search parameters included English language, adolescent 13-18 years of age, and articles published between 2013 and 2018. The search yielded 145 articles. After removing duplicates, conference abstracts, and dissertations, 35 relevant articles focusing on the concept of pediatric to adult healthcare transition related to self-management of adolescents with T1DM were included in this literature review.

Literature Synthesis

Current literature provides limited understanding about predictors of successful transition of the adolescent with T1DM to adult health care and the effect of adolescent centered healthcare practices on the adolescent with T1DM (Farrell et al., 2018; Hansen & Jensen, 2017). Fifteen studies centered on the behaviors and conditions of self-management (Farrell et al., 2018; Kapellen, et al., 2018; Carlsen et al., 2017; Sawicki et al., 2017; Wong, 2017; Beal et al., 2016; Joley, 2016; Quinn, et al., 2016; Hagger et al., 2016; White et al. 2015; Raymond, 2015; Sheehan et al., 2014; Helgeson et al., 2014; Wiebe et al., 2014; Lyons et al., 2014; Rollo et al., 2014) while six studies evaluated disease-specific or developmentally-specific transitional programs (Wong, 2017; Campbell et al., 2016; Chu et al., 2015; Egan et al., 2015; Little et al., 2016; Mistry, et al., 2015; Los et al., 2016; Maiorino, et al., 2014). Ten studies focused on both the parent and adolescent perspectives of independent self-management of the adolescent with T1DM (Bomba et al., 2017; Hansen & Jensen, 2017; Castensøe-Seidenfaden et al., 2016; Babler & Strickland, 2016; Ersig et al., 2016; Babler & Strickland, 2015; Joley, 2015; Polfuss et al., 2015; Fernandez et al., 2014; Sullivan-Bolyai et al. 2014), but only four focused solely on the adolescent perspective (Bomba et al., 2017; Hansen & Jensen, 2017; Babler & Strickland, 2016; Babler & Strickland; 2015). Nine transitional research articles included adolescents and young adults with special needs and numerous other chronic diseases in addition to T1DM, such as spina bifida (Beal et al., 2016), autism (Beal et al., 2016), Turner Syndrome (Beal et al., 2016), irritable bowel disease (Bomba et al., 2017; Schmidt et al., 2016) and cystic fibrosis (Bomba et al., 2017; Schmidt et al., 2016) Two studies included adolescents with all chronic diseases within healthcare systems (Sawicki et al., 2017; Fernandez, O'Sullivan-Oliveira, Landzberg, Khairy,

Melvin et al., 2014) and four literature reviews included adolescents with all chronic health conditions (Joly, 2016; 2015; Chu et al., 2015; Campbell et al., 2016). Two articles examined the use of technology on independent self-management of T1DM (Los et al., 2016; Maiorino et al., 2014). This chapter will synthesize and discuss the current literature on the behaviors and conditions of self-management, the disease – and developmental-specific transitional programs, the influence of technology on independent self-management, and parent and adolescent perceptions of facilitators and inhibitors of independent self-management of the adolescent with T1DM.

TABLE 1. *Literature review to identify the concept of transition related to adolescent T1DM self-management.*

Author/Year/Title	Keywords	Design/Aims	Sample/Measures	Results
Babler & Strickland (2015) Helping Adolescents with diabetes "Figure it out."	Type 1 diabetes; adolescents; normalizing; self-management	Grounded Theory To gain a greater understanding of adolescent's experiences living with T1DM Create a theoretical paradigm Generate hypotheses for further study	Fifteen 11-15-year-olds/ In-home interviews	Theoretical model created called "Normalizing " Diabetes is the new normal; Figuring it out: the realization that you can manage your diabetes and maintain glucose control, accept diabetes and stay on tracking it out
Babler & Strickland (2016) Moving the journey towards independence: Adolescents transitioning to successful diabetes self-management	Self-management; type 1 diabetes; adolescent; conflict; parent	Grounded theory/ Develop a paradigm from the perspective of the adolescent that help to predict, describe and explain behaviors	Fifteen 11-15-year-olds/ In-home interviews	Theoretical model created called "Normalizing " Diabetes is the new normal Taking over care Experiencing conflict with the parent Realizing diabetes is hard Major tasks: separating from parent and independently managing their diabetes**.**
Beal, Riddle, Kichler, Duncan, Houchen et al. (2016) The associations of chronic condition type and individual characteristics with transition	Adolescent chronic conditions; health care transition; transition readiness; young adult	Quantitative /Identify differences in healthcare transition readiness based on chronic conditions	A total of 163 12-22 years old with chronic conditions	TRAQ scores (M = 3.13; SD = 0.87) could range from 1 to 5. Literacy scores (M = 11.70; SD = 1.86) could range from 0 to 14; AYA with ASD reduced TRAQ scores by B = −20.99 ($P < .01$); AYA with spina bifida reduced scores by B = −10.82 ($P = .03$) AYA with TS reduced scores by B = −8.51 ($P = .03$)

TABLE 1 – *Continued*

Author/Year/Title	Keywords	Design/Aims	Sample/Measures	Results
				Youths with T1DM did not statistically differ from youth without chronic conditions.
Bomba, Herrmann-Garitz, Schmidt, Schmidt, & Thyen, (2017) An assessment of the experiences and needs of adolescents with chronic conditions in transitional care: a qualitative study to develop a patient education program	Adolescents with chronic health conditions; empowerment; group Training; patient education; transition	Qualitative: To explore the experiences and needs of adolescents with chronic conditions in the transition period/To apply findings to the design of a generic patient education program.	29 >/= 15 years old with T1DM (n = 12), Cystic fibrosis (n = 7), and IBD (n = 10). group (n = 18) or individual (n = 11) interviews Data were analyzed using qualitative content analysis	Seven themes identified: Peer support, future and vocational issues, disease knowledge, transfer to adult medicine, changes in the doctor-patient relationship, detachment from parents, own health management and health system, and implementation and methods of transition training. patient education programs promoting adolescent self-management and empowerment increase preparedness for transition, adolescents would benefit from opportunities to exchange ideas and more specific
Campbell, Biggs, Aldiss, O'Neill, & Clowes et al. (2016) Transition of care for adolescents from pediatric services to adult health services	Randomized controlled trials; controlled before- and after-studies; interrupted time-series studies; transition of care; adolescents	Systematic literature review/To evaluate the effectiveness of interventions designed to improve the transition of care for adolescents from pediatric to adult health services.	Four articles Cochrane Central Register of Controlled Trials 2015, Issue 1, MEDLINE, EMBASE, PsycINFO, and Web of	Limited range of interventions and studies, limited numbers of clinical conditions, short-term follow up not reflective of the lengthy process of transition, made the effectiveness of evaluation of interventions difficult.

TABLE 1 – *Continued*

Author/Year/Title	Keywords	Design/Aims	Sample/Measures	Results
Carlsen, Skrivarhaug, Thue, Cooper, & Goransson et al. (2017) Glycemic control and complications in patients with type 1 diabetes-a registry-based longitudinal study of adolescents and young adults	Diabetes complications; diabetes mellitus type 1; HgbA1C; glycosylated; registries; transition to adult care	Longitudinal population-based design/ To assess longitudinal glycemic control and the prevalence of retinopathy and neuropathy in young people with type 1 diabetes in Norway.	A total of 874 subjects aged 14-30 years old	HgbA1C increased through adolescence to peak at 17yo for females and 19yo for males. Females HgbA1C higher (9.3) than males (9.1); Median HgbA1C declined but still > 8 for patients approaching 30yo; 50% of subjects 14-17yo and 40% of subjects 18-25yo had HgbA1C > 9.3. Retinopathy found in 16% of subjects; Nephropathy found in 13% of subjects; Patient transferring from pediatric- adult health between 14-17yo had higher mean HgbA1C, higher prevalence of late complications and higher % of ex- and daily smokers than those transferring between 18-22yo <40% with albinuremia treated with ACE inhibitors or ARBs.
Castensøe-Seidenfaden, Teilmann, Kensing, Hommel, & Olsen et al. (2016) Isolated thoughts and feelings and unsolved concerns: adolescents' and parents' perspectives on living with type 1 diabetes- a qualitative study using visual storytelling	Adolescence; qualitative methods; self-management; transition; type 1 diabetes; visual storytelling	Qualitative explorative/ To explore and describe the experiences of adolescents and their parents living with T1DM To identify the needs for support to improve adolescents' self-	Nine adolescents and their parents/ Individual interviews Visual storytelling	Four major themes: Striving for safety, striving for normality, striving for independence, worrying about the future Parents and adolescents share similar concerns and experiences but handle them differently. Adolescents and parents hesitate to share their thoughts and feelings which leads to unresolved challenges and

TABLE 1 – *Continued*

Author/Year/Title	Keywords	Design/Aims	Sample/Measures	Results
		management skills in transition to adulthood.		concerns, misunderstandings, frustrations and loneliness.
Chu, Maslow, von Isenberg, & Chung (2015) Systematic review of the impact of transition interventions for adolescents with chronic illness on transfer from pediatric to adult healthcare	Adolescents; chronic illness; healthcare transfer; healthcare transition; young adults	Systematic literature review/To examine the current evidence regarding the effect of transition interventions on care transfer	Five articles Medline, CINAHL, and PsycINFO/ databases.	Follow up: Range = 3-24 months. 3/5 studies found successful transition following a transition intervention. 2/5 studies showed no statistically significant effects. 3/5 transition programs measured post-transfer HgbA1C: 1 showed improved HgbA1C rates.
Egan, Corrigan, & Shurpin (2015) Building the bridge from pediatric to adult diabetes care: making the connection.	Transition program; emerging adults; type 1 diabetes; adult health care; transition process; diabetes-related distress; quality of life; health care provider autonomy & support; adherence	Mixed methods; Longitudinal design/ To evaluate the effectiveness and outcomes of a structured transition program for emerging adults with type 1 diabetes	Twenty-nine AYA with T1DM 18-28 years old, (3 boys, 27.3% and eight girls, 72.7%) ages 11 to 15 years old (mean, 13.9), and 15 parents/ Likert scale surveys Pre-post transition open-ended, qualitative questionnaires DDS, DQOLY-SF, HCCQ	HgbA1C of 8.2% (range, 7.2%-9.2%; median, 8.4) Phase 1: Remembering the beginning of the journey: getting the diagnosis, learning about diabetes and its management, recognizing my life is changing Phase 2: Balancing blood sugars/ preventing a crisis: recognizing symptoms of low and high blood sugar, monitoring, action, adjusting diet and activity to balance blood sugars, evaluating results from trying to balance blood sugars, and seeking help and experiencing consequences from not keeping the blood sugars balanced. Phase 3: Integrating diabetes into the world outside the home:

TABLE 1 – *Continued*

Author/Year/Title	Keywords	Design/Aims	Sample/Measures	Results
				building support and realizing I'm different. Phase 4: Moving the journey toward independence: taking over care, experiencing conflict with parents, and realizing diabetes is hard. Phase 5: Figuring it out: accepting diabetes, believing it's possible to manage diabetes, showing responsibility, and staying on track. Phase 6: Helping others: Mentoring, showing compassion to others, and planning for a future helping others.
Ersig, Tsalikian, Coffey, & Williams (2016) Stressors in teens with type 1 diabetes and their parents: Immediate and long-term implications for transition to self-management.	Anxiety; family; parents; stress; teenagers; type 1 diabetes	Qualitative descriptive/To identify stressors of teens with T1DM and their parents related to the impending transition to adulthood.	Fifteen teens with T1DM and 25 parents from 16 families/One-time structured telephone interviews	Themes for teens: Ineffective self-management Anticipatory worry Parental themes: Transfer of management responsibility Anticipatory worry. Healthcare transition themes: Changes in health insurance Resources for T1DM management
Farrell, Fernandez, Salamonson, Griffiths, & Holmes-Walker (2018)	Clinic attendance; diabetic ketoacidosis; glycated	Retrospective Study Medical record audit/ To identify	A total of 439 AYA (median age 18 years old)/ Data collected from	HgbA1C < 7.5% achieved by 23% at baseline, 22% at 18 months an 20% at 30 months.

TABLE 1 – *Continued*

Author/Year/Title	Keywords	Design/Aims	Sample/Measures	Results
Health outcomes for youth with type 1 diabetes at 18 months and 30 months post transition from pediatric to adult care	hemoglobin; transition; type 1 diabetes mellitus	determinants of HbA1c at 18 and 30 months following a transition in young people with T1DM to a youth-specific diabetes service To evaluate the impact of the service on acute admissions with DKA over 14 years	medical record of young people who transitioned from pediatric to adult healthcare	Glycemic control at first visit predictive of subsequent glycemic control. 8.6% lost to follow up. Hospital admissions and readmissions for DKA reduced from 72% to 4% (p <0.001) Mean length of stay decreased from 6.56-2.36 days (P<0.001).
Fernandez S. M., O'Sullivan-Oliveira, J., Landzberg, M. J, Khairy, P., Melvin, P. et al. (2014) Transitioning and transfer of adolescents and young adults with pediatric-onset chronic disease: The patient and parent perspective.	Health care transition; self-care management, pediatric-onset chronic disease	Mixed Methods/ To determine patients and parents' perceptions of transitioning education and their attitudes and perceived barriers to transfer to adult-oriented care.	A total of 155 16-25-year-olds with chronic pediatric-onset conditions and 104 parents/ Survey/Questionnaire Individual interview N=Parent/Adolescent Cancer (n=21/23) T1DM 10/25 Congenital heart disease 13/21 Juvenile rheumatoid arthritis 10/20 Hematologic disorder 16/15 IBD 12/16 Cystic fibrosis 5/11 Solid organ transplant 6/7 Genetic disorders 5/5 Dialysis 0/4	Less than 50% of AYA and parents reported receiving education on reproductive health, the impact of disease on future offspring, birth control and risks of pregnancy. AYA more likely to receive education on unprotected intercourse (43% vs. 18%, p<0.001) and birth control (45% vs 23% p=0.009), the risk of alcohol (61% vs 38%, p<0.001) and illicit drug use (48% vs 34%, p=0.019). Only 28% of AYA and 31% of parents received education on the impact of disease on future vocations. 56% of AYA and 58% of parents anticipated readiness for transfer

TABLE 1 – *Continued*

Author/Year/Title	Keywords	Design/Aims	Sample/Measures	Results
			Other 6/9	from pediatric to adult healthcare before age 25 years. Qualitative themes: Fear and success
Hagger, Hendrieckx, Sturt, Skinner, & Speight (2016) Diabetes distress among adolescents with type 1 diabetes: A systematic review	Adolescent, type 1 diabetes, emotions, psychological stress, distress, review	Systematic Review Investigating the prevalence of DD, demographic, clinical, behavioral and psychosocial correlates of DD and interventions that reduce DD in adolescents with T1DM	Twenty-seven articles reporting on 16 studies/ Medline, CINAHL, SCOPUS, and PsycINFO	1/3 adolescents experience elevated DD. Three measures of DD have been developed specifically for adolescents
Hansen & Jensen (2017) Partnership in transition: Experiences of adolescents with type 1 diabetes	Type 1 diabetes; adolescents; transition; partnership; patient experience; qualitative methods	Qualitative descriptive/ To explore how adolescents with T1DM experience partnerships in transition	Ten 17 and 18-year-olds with T1DM/Audiotaped interviews NVivo 10. Inductive data analysis	3 Main themes: Transition unawareness The crucial change in relationship with health care providers Partnership with shared-decision making
Helgeson, Reynolds, Siminerio, Becker, & Escobar (2014) Cognitive adaptation theory as a predictor of adjustment to emerging adulthood for youth with and without type 1 diabetes	Cognitive adaptation theory; diabetes; emerging adult; resilience	Quantitative longitudinal study/ The purpose of the study was to determine whether resilience, defined by cognitive adaptation theory, predicted emerging.	Youth (average age 18 53% female, and 93% white) with (n = 118) and without type 1 diabetes (n = 122), On-line questionnaires during senior year of high school and two years later.	Youth during their senior year of high school with high levels of self-esteem, mastery, and optimism showed a better adjustment to emerging adulthood one and two years after transition.

TABLE 1 – *Continued*

Author/Year/Title	Keywords	Design/Aims	Sample/Measures	Results
		adulthood outcomes among youth with and without type 1 diabetes		In AYA with T1DM, CAT predicted lower levels of bulimic symptoms, friend conflict, romantic relationship breakup, and alcohol use. It is important to identify youths with low self-esteem, personal control, and optimism during adolescence to prevent poor outcomes as young adults, especially in adolescents with T1DM.
Hilliard, Perlus, Clark, Haynie, Plotnick et al. (2014) Perspectives from before and after the pediatric to adult care transition: A mixed-methods study in type 1 diabetes.	Adherence; children and adolescents; fatherhood; type 1 diabetes	Mixed-method To understand the concerns, expectations, preferences, and experiences of pretransition adolescents and parents and posttransition young adults	Twenty adolescents 15-17 years old pre-transition from pediatric to adult care 59 young adults 18-22 years post-transition/ Questionnaire Interviews	Most pretransition adolescents had not yet discussed transferring care with their parents or doctors. Many posttransition young adults reported positive, supportive interactions, several described challenges locating or establishing a relationship with an adult diabetes care provider. Qualitative themes related to the anticipated timing of transfer, early preparation for the transition, desire for developmentally appropriate interactions with providers, maintenance of family and social support, and strategies for coordinating care between pediatric and adult care providers.

TABLE 1 – *Continued*

Author/Year/Title	Keywords	Design/Aims	Sample/Measures	Results
Joley (2016) Integrating transition theory and bioecological theory: A theoretical perspective for nurses supporting the transition to adulthood for young people with medical complexity	Adolescent; advanced nursing practice; Ecological Theory; framework; medically fragile; Transition Theory; transition to adulthood; young adult.	Integrative literature review/ To present a discussion integrating Meleis' Theory of Transition and Bronfenner's Bioecological Theory of Human Development to inform nursing and advanced practice in support of adolescent transition to adulthood	Articles, informal discussions with families and the author's experience/ CINHAL and Medline of articles between 2004-2014	Advocate, prepare, inform and build skills and help to create a new adult-oriented microsystem. Engage with adolescents to understand existing components of their context and create new goals and actions necessary for goal attainment Preparation starts before a contextual change Create developmentally appropriate-based transition preparation programs. Identify individual dependencies on microsystem components to access appropriate resources and achieve independence.
Joly, (2015) Transition to adulthood for young people with medical complexity: An integrative literature review	Adolescent; advanced nursing practice; Ecological Theory; framework; medically fragile; Transition Theory; transition to adulthood; young adult.	Integrative literature review /To explore how the empirical literature on the transition to adulthood for young people with medical complexity can inform nursing and advanced practice.	Eleven empirical studies CINHAL and Medline, published since 2003.	Three emerging themes: It's like falling off a cliff The paradox of independence. It takes a village
Kapellen, Müther, Schwandt, Grulich-Henn, Schenk et al. (2018) Transition to adult diabetes care in Germany- High risk for acute	Adolescents; emerging adults; metabolic control; transition; type 1 diabetes	/ To compare metabolic control, acute complications, and microvascular complications in AYA	A total of 1283 young adults with T1DM in pediatric and adult health centers in Germany/ Chart data collection	HbA1c increased significantly from 8.95% (74 mmol/mol) before to 9.20% (77 mmol/mol) in the first year after transition. Frequency of DKA with

TABLE 1 – *Continued*

Author/Year/Title	Keywords	Design/Aims	Sample/Measures	Results
complications and declining metabolic control during the transition phase		before and after transfer to an adult health center		hospitalization (0.10-0.191 per annum, P < .0001) and severe hypoglycemia (0.23-0.46 per annum, P = .013) doubled during transition. Microvascular complications increased depending on the time between the first visit in adult treatment and last visit in pediatric care. No significant correlation increased microvascular complications to the duration of the transition.
Little Odiaga & Minutti (2016) Implementation of a diabetes transition of care program	Adolescents, diabetes, transition program, transitioning care	Quantitative Pilot study/ To evaluate transitional readiness of AT1DM	A total of 33/39 identified AT1DM >/= 14years old from transition registry / Diabetes transition data registry TRAQ/transition planning	Baseline TRAQs in 21 (64%) of the 33 identified patients, with a mean TRAQ skill score of 66.62 out of 100. There was no correlation between better TRAQ scores and hemoglobin HgbA1c level. Lower baseline TRAQ scores for appointment keeping and tracking health issues. The confidence showed in managing daily activities, talking with providers, and managing medications.
Los, Ulrich, & Guttman-Bauman (2016) Technology use in transition-age patients with type 1 diabetes	Adolescence, continuous glucose monitor, emerging adulthood, insulin pump, transition, telemedicine, type 1 diabetes	Review of literature/To review the current use of technology in patients with T1DM transitioning from pediatric to adult care and discuss the		Insurance coverage restricts patterns of prescribing technology devices for daily management. Use of telehealth in transition-age youth with T1DM needs further study. Reimbursement for

TABLE 1 – *Continued*

Author/Year/Title	Keywords	Design/Aims	Sample/Measures	Results
		potential to improve transition process outcomes.		telehealth services is crucial to improving access to needed services. Technology related to diabetes control and management should be integrated.
Lyons, Becker, & Helgeson (2014) Transfer from pediatric to adult healthcare: effects on diabetes outcomes	The transfer from pediatric to adult healthcare for emerging adults with T1DM has received increasing attention in the literature.	Literature review/To analyze the effect of the transfer from pediatric to adult healthcare for emerging adults with T1DM on outcomes of diabetes care visit attendance, glycemic control, and diabetes-related complications To assess the methodological strength of the current observational and interventional data.	Eighteen observational and interventional studies/ PubMed and Embase computerized databases search	Observational studies are limited but report declines in diabetes care visits but improvement or no change in HbA1c post-transfer to adult care. Studies reporting results of transition interventions lack control groups and data collection pre- and post-transfer of care. Few methodologically strong studies are available to guide clinicians with the transition from pediatric to adult care
Maiorino, Bellastella, Petrizzo, Improta, Brancario et al. (2014) Treatment satisfaction and glycemic control in young type 1 diabetic patients in transition from pediatric health care: CSII versus MDI.	CSII, type 1 diabetes, transition, treatment satisfaction	Quantitative /To evaluate whether CSII has any advantage over MDI on glycemic control and treatment satisfaction in young patients with Type 1 diabetes in transition to an adult diabetes center	A total of 125 patients on MDI/DTSQ evaluated in all patients at baseline and after 12 weeks	DTSQ score lower in CSII group (21.1 [+ or -] 8.8 vs. 25.1 [+ or -] 7.1, P = 0.011). After 12 weeks, decrease in HbA1C was observed in both groups [difference -0.3 % (95 % CI -0.6 to 0.1, P = 0.847)]. Mean amplitude glucose excursions, blood glucose standard deviation, and overall hypoglycemia was significantly

TABLE 1 – *Continued*

Author/Year/Title	Keywords	Design/Aims	Sample/Measures	Results
				reduced in the CSII group. DTSQ overall score increased in CSII and decreased in MDI (difference between groups = 9.9, 95 % CI 8.0--12.0, P < 0.001), perceived hyperglycemia and hypoglycemia decreased in CSII compared with MDI (difference: -2.5 and -2.0, respectively, P < 0.001 for both)
Mistry, Van Blyderveen, Punthakee, & Grant (2015) Condition-related predictors of successful transition from pediatric to adult care among adolescents with type 1 diabetes	Adolescent; combined modality therapy; diabetes type 1; hemoglobin A1C; insulin/administration; transition to adult care; follow up	Qualitative descriptive/ To describe patient attendance for adult treatment after completion by young people of a structured diabetes transition clinic. To identify predictors of non-attendance at adult clinics by young people with type 1 diabetes transitioning from pediatric care	A total of 136 young people participating in a diabetes transition clinic/ Clinical interviews	43 participants were lost to follow up: were most commonly found to be diagnosed with T1DM before the age of 12, those using MDI, those with higher pre-transition HgbA1Cs, those with poor pediatric follow up the year before transfer, and those who did not engage in the diabetes transition clinic.
Polfuss, Babler, Bush, & Sawin (2015) Family perspectives of components of diabetes transition program	Adolescents; type 1 diabetes; self-efficacy; transition program; self-management	Prospective cross-sectional/ To evaluate the perspectives of adolescent /parent dyads about a diabetes program	Forty-five 16-20-year-old/parent dyads from 51 families/ Questionnaires Data analysis included frequencies, correlations, Cronbach's alpha and paired t-tests.	Dyad knowledge and self-efficacy were rated as high. Disagreement existed amongst parents and adolescents in behaviors important for the transition. Adolescents rated attending regular visits and talking with parents as most helpful and

TABLE 1 – *Continued*

Author/Year/Title	Keywords	Design/Aims	Sample/Measures	Results
				talking with providers and program materials as helpful for the transition. Adolescent and parent assessment of adolescent self-efficacy and self-management behaviors strongly correlated. Family dyad's perceptions of adolescent self-efficacy were similar but not related to HbA1C
Quinn, Ambrosino, Doyle, Weyman, Tamborlane et al. (2016) Utility of psychological screening of young adults with type 1 diabetes transitioning to adult providers	Type 1 diabetes HbA1C = Hgb A1c YCDP = Yale Children's Diabetes Program PHQ-8 = Patient Health Questionnaire-8 DDS, DEPS-R	Quantitative/ To examine the utility of screening for psychological disorders using two disease-specific and one general measure at the time of transition from pediatric to adult care	Forty-three young adults with T1DM /Patient Health Questionnaire, the DDS, and the Diabetes Eating Problem Survey-Revised. Chart review Metabolic data	Depression, diabetes distress, and disordered eating positively correlated with glycated hemoglobin (HbA1c) ($r = 0.31$, $P = .05$; $r = 0.40$, $P = .009$; $r = 0.63$, $P<.001$, respectively), disordered eating accounted for the majority of observed variance ($df = 1$; $F = 18.6$; $P<.001$). HbA1c was higher in patients with versus without disordered eating ($P<.001$), body mass index did not differ between the two groups ($P = .51$)
Raymond (2015) Updates in behavioral and psychosocial literature in adolescents with type 1 diabetes	Adolescents; behavioral; pediatrics; psychosocial; type 1 diabetes	Literature update/ To review updates in adolescent diabetes literature between February 2014 and February 2015. To highlight new research in the behavioral and psychosocial literature.	Thirty-three articles	Behavioral and psychosocial concerns remain prevalent in adolescents with type 1 diabetes, psychological needs are not being met, and current interventions have not been largely successful in impacting outcomes

TABLE 1 – *Continued*

Author/Year/Title	Keywords	Design/Aims	Sample/Measures	Results
		focused on type 1 diabetes in adolescents		
Rollo, Salardi, Ciavarella, Forlani, Scipione et al. (2014) Transition from pediatric to adult care. Eight years after the transition from pediatric to adult diabetes care: Metabolic control, complications and associated diseases.	Type 1 diabetes; transition; metabolism control; microvascular complications; psychological-psychiatric disorders	Quantitative/ To compare the metabolic control of pediatric and adult care. To evaluate the presence of complications, associated diseases, and psychological and psychiatric disorders	A total of 73% (69/94) patients with T1DM from a single clinic who transferred to adult healthcare centers between 1985 and 2005 HgbA1C, diabetic complications, associated diseases	Mean HgbA1C during the pediatric, transition and adult period (8.4 +/- 1.8%, 8.3 +/- 1.4% and 8.4 +/- 1.3% respectively). 13 patients dropped out, and their mean HgbA1C was 10.4%. 35/69 patients had retinopathies, 12/69 nephropathies, 18.3% thyroid disease, 11.2% depression, 9.8% benign neoplasm, and 5.6% drug or alcohol addictions.
Sawicki, Garvey, Toomey, Williams, Hargraves et al. (2017) Preparation for transition to adult care among Medicaid-insured adolescents	Youth with chronic illnesses; transition preparation; transition self-management; prescription management; transfer planning	Quantitative/ To determine the quality of transition preparation using ADAPT	A total of 1355 adolescents with chronic health conditions from 2 different health plans/ ADAPT Mailed Survey of youth with chronic illness	Case mix adjusted ADAPT composite scores low in both plans- highest scores in counseling on prescription medicine (57% and 58%) and lowest scores were for transfer planning (5% and 4%) Health plan 1 had a higher score for counseling on transition self-management (36% vs. 30%, $P < .001$) no significant difference in composite scores across samples. No significant differences with adjustments to gender or type of health plan or type of chronic condition.

TABLE 1 – *Continued*

Author/Year/Title	Keywords	Design/Aims	Sample/Measures	Results
Schmidt, Herrmann-Garitz, Bomba, & Thyen (2016) A multicenter prospective quasi-experimental study on the impact of a transition-oriented generic patient education program on health service participation and quality of life in adolescents and young adults	Transition; chronic condition; patient education; group training; patient group training; patient training; transition workshop; adolescents; cystic fibrosis; diabetes; inflammatory bowel disease	Controlled trial Prospective quasi-experimental study/ To test the effects of a generic transition-oriented patient education program on adolescents' health service participation and QOL	A total of 274 (mean age 16.8 years, SD 1.76) with T1DM, CF or IBD from 29 transition workshops/ TCS, GSE, PAM13-D, CHS-SUN, and 3 QOL scales Assessed at baseline and six months follow up.	The intervention did not significantly affect patient satisfaction and QOL however, the post-hoc analysis suggested different effects across conditions. The intervention group showed highly significant improvement in transition competence, self-efficacy and satisfaction with school services at six months follow up. No significant differences were found relating to QOL, patient activation, and general satisfaction with care. Post-hoc analysis showed significant outcomes in subgroups with diabetes and IBD. Descriptive analysis shows minimal changes in outcomes of the control group, but only in participants < 18 years old.
Sheehan, While, & Coyne (2014) The experiences and impact of transition from child to adult healthcare services for young people with type 1 diabetes: A systematic review	Transition; young people with type 1 diabetes; independent self-management; self-advocacy skills; glycemic control; diabetes-related hospitalization; attendance; accessing and maintaining diabetes health care	Systematic literature review To explore the impact and experiences of transition between child and adult health services for young people withT1DM.	Forty-three studies/ PubMed, Embase, CINAHL and PsycINFO computerized databases	Three themes: Discontinuity of care, renegotiating responsibility for disease management, and psychosocial and practical issues. There were mixed results regarding glycemic control and diabetes-related hospitalizations. All studies found worse attendance following transfer

TABLE 1 – *Continued*

Author/Year/Title	Keywords	Design/Aims	Sample/Measures	Results
				Young people and parents experienced greater difficulty in accessing and maintaining diabetes health care while experiencing transition. Some young people were inadequately prepared for the independent self-management and self-advocacy skills required post-transfer.
Sullivan-Bolyai, Bova, Johnson, Cullen, Jaffarian et al. (2014) Engaging teens and parents in collaborative practice	Teens and parents; type 1 diabetes; self-management; family management; resources; transition	Qualitative exploratory/ To describe the perspective of teens and their parents about self-management knowledge, behaviors, and resources used to manage T1DM	Ten teenagers segmented by HgbA1C value, 13 parents/ Separate teen-parent focus groups Qualitative content analysis	Teens varied in interest in learning more about T1DM and management. Teens diagnosed at a very young age reported not knowing anything else but diabetes, while those diagnosed later were more active in the learning process. No benefit to diabetes camp or peer groups reported. Diabetes, All the teens, were interested in "helping others" with diabetes. Parents shared common struggles with the transition of self-management responsibilities, with variation in parenting styles. A small group of parents had difficulty balancing their “job” of encouraging self-management with the pressure from the health care providers to do the care

TABLE 1 – *Continued*

Author/Year/Title	Keywords	Design/Aims	Sample/Measures	Results
				physically. Parents and teens reported wanting less focus on blood glucose levels and more on the whole person. All participants reported difficulty with scheduling appointment and were concerned with long waiting times.
White, O'Connell, & Cameron (2015) Transition to adult endocrine services: What is achievable? The diabetes perspective	Adolescent; diabetes mellitus; transition to adult care; type I; young adult	Literature review /To review the current transitional literature base and highlight areas which warrant further study.	Did not specify	The glycemic trajectory of adolescents with T1DMs is set in late adolescence. 1/3 of young adults with T1DM become lost to follow up during transition Poor pediatric clinical attendance higher HgbA1C at transition, history of mental health disorders and older age increase risk for poor outcomes
Wiebe, Chow, Palmer, Butner, & Butler (2014) Developmental processes associated with longitudinal declines in parental responsibility and adherence to type 1 diabetes management across adolescence	Adherence, adolescents, longitudinal research, parenting, puberty, self-efficacy, type 1 diabetes	Quantitative longitudinal study/ To identify whether changes in pubertal status and self-efficacy for diabetes management are associated with longitudinal declines in parental responsibility for diabetes To determine whether	A total of 252 AT1DM, mothers, and 188 fathers/ Self-reports every 6 months (6 time points) over 2.5 years	Parental responsibility decreased linearly over time, with between-subject variability in both the latent intercepts (initial level) and slopes (rate of change over time) (ps < .05). Families were generally sharing responsibility for diabetes tasks at baseline (average intercepts of 2.591 (standard error, SE = .039), 2.886 (SE = .036), and 2.938 (SE = .045) for adolescent, mother, and father report). By end of the study, adolescents were assuming

TABLE 1 – *Continued*

Author/Year/Title	Keywords	Design/Aims	Sample/Measures	Results
		these factors moderate associations between declining parental responsibility and deteriorating adherence across adolescence		primary but not sole responsibility for diabetes (average slopes across time of −.090 (SE = .007), −.109 (SE = .005), and −.103 (SE = .008) for adolescent, mother, and father report Declines in parental responsibility were related to deterioration in adherence especially when adolescents did not report concomitant growth in self-efficacy. (b(SE) = .241 (.142), p > .05, but this association was moderated by more rapid growth in self-efficacy) A significant interaction between the slopes of adolescent-reported self-efficacy and parental responsibility predicted the slope of adherence, b(SE) = −1.522 (.001), p < .01.
Wong (2017) Effect of financial incentives on glucose monitoring adherence and glycemic control among adolescents and young adults with type 1 diabetes	Financial incentives; improved adherence to daily glucose monitoring goals and glycemic control	Randomized clinical trial/ To determine the effect of daily financial incentives on glucose monitoring adherence and glycemic control in AYA with T1DM	Ninety AYA 14-20 years old from the Diabetes Center at CHOP/ Investigator-blinded, 6-month, 2-arm study with 3-month intervention	Intervention group showed significantly greater adherence to glucose monitoring goals in the incentive period (50.0% vs 18.9%; adjusted difference, 27.2%; 95% CI, 9.5% to 45.0%; P = .003) but not in the follow-up period (15.3% vs 8.7%; adjusted difference, 3.9%; 95% CI, -2.0% to 9.9%; P = .20). The change in

TABLE 1 – *Continued*

Author/Year/Title	Keywords	Design/Aims	Sample/Measures	Results
				HbA1c levels from baseline did not differ significantly between groups at 3 months (adjusted difference, -0.08%; 95% CI, -0.69% to 0.54%; P = .80) or 6 months (adjusted difference, 0.03%; 95% CI, -0.55% to 0.60%; P = .93).

AYA- Adolescents and Young Adults; T1DM=Type 1 Diabetes Mellitus; AT1DM= Adolescent with T1DM; TS= Turner Syndrome; ASD= Autism Spectrum Disorder; TRAQ= Transition Readiness Assessment Questionnaire; RTQ-T = Readiness for Transition Questionnaire-Teen; TRIP= Transition Readiness Investigation Project; RCT= randomized control study; DDS= Diabetes Distress Scale; DEPS-R = Diabetes Eating Problem Survey-Revised; DQOLY-SF= Diabetes Quality of Life Youth-Short Form; HCCQ= Health Care Climate Questionnaire; DD= Diabetes distress; CSII= continuous subcutaneous insulin infusion; MDI= multiple daily injections; HgbA1C= Glycated hemoglobin; MDI = multiple dose insulin injection; BG= blood glucose; QOL = quality of life; CF = cystic fibrosis; IBD = Irritable bowel disease; ADAPT = Adolescent Assessment of Preparation for Transition; TCS= Health-related transition competence scale; GSE= General self-efficacy scale; PAM13= Patient activation measure 13; CHS-SUN= self-satisfaction with healthcare

Behaviors and Conditions of Self-Management

This literature review identified two major conditions of transition of the adolescent with T1DM from dependent to independent self-management (Farrell et al., 2018; Kapellen et al., 2018; Carlsen et al., 2017; Sawicki et al., 2017; Beal et al., 2016; Joley, 2016; Quinn et al., 2016; Hagger et al., 2016; White et al., 2015; Raymond, 2015; Sheehan et al., 2014; Helgeson et al., 2014; Wiebe et al., 2014; Lyons et al., 2014; Rollo et al., 2014). These conditions include developmental conditions and health-illness conditions. Studies that have focused on the concept of transition readiness of adolescents with chronic illnesses to the adult healthcare system (Sawicki et al., 2017; Beal et al., 2016; White et al. 2015; Sheehan et al., 2014) have found differences in levels of transition readiness for adolescents based on their chronic disease (Beal et al., 2016) Deficiencies in the preparation of the adolescent with T1DM for independent self-management include areas of continuity of care and poor attendance and follow up with pediatric providers, renegotiating responsibility for disease management from parent to child, and psychosocial issues such as co-morbid mental illness and inadequate self-management and self-efficacy skills (White et al., 2015; Sheehan et al., 2014).

Health-Illness Conditions

Multiple long-term and permanent complications related to poor glycemic control have been associated with transitions of adolescents with T1DM to adult healthcare (Kapellen et al., 2018; Carlsen et al., 2017; Rollo et al., 2014). These complications include retinopathy, nephropathy, albinuremia, and other microvascular complications (Kapellen et al., 2018; Carlsen et al., 2017; Rollo et al., 2014) Increased frequencies of hospitalizations and severe hypoglycemia have also been associated with the transition period (Kapellen et al., 2018)

Current studies to guide healthcare providers with the transition of adolescents with T1DM from pediatric to adult care are limited (Lyons et al., 2014). The current data on the transition of adolescents with T1DM to adult healthcare has shown that diabetes healthcare visits decline during the transitions of adolescents with T1DM and that HgbA1C levels are generally higher following transitions (Farrell et al., 2018; Lyons et al., 2014). A medical record audit of young people who transitioned from pediatric to adult healthcare found that glycemic control during their pre-transition visit was predictive of subsequent glycemic control (Farrell et al., 2018). Co-morbidities and other autoimmune diseases commonly found in adolescents with T1DM such as thyroid disease, diabetes distress, depression, disordered eating, and drug or alcohol addictions have been found to be positively correlated with elevations in HgbA1C (Hagger et al., 2016; Quinn et al., 2016; Rollo et al., 2014).

Discrepancies in the age of transfer of adolescents with T1DM to adult healthcare have been found (Carlsen et al., 2017). Patient transferring from pediatric- adult health between 14-17yo had higher mean HgbA1C, and a higher prevalence of late complications of T1DM than those transferring between 18-22 years old (Carlsen et al., 2017). They were also more likely to have a smoking history (Carlsen et al., 2017).

Developmental Conditions

Current research has identified the need for developmentally appropriate preparation before a contextual transition to independent self-management occurs (Helgeson et al., 2014; Joley, 2016; Raymond, 2015; Wiebe et al., 2014). Healthcare providers need to engage with adolescents to understand the existing components of their context and dependencies on resources and create new goals and actions necessary for goal attainment (Joley, 2016). A study

found that adolescents with T1DM with high levels of self-esteem, mastery, and optimism showed a better adjustment to emerging adulthood one and two years after their transition (Helgeson et al., 2014). However, psychological needs are not being met, and current interventions have not been successful in impacting outcomes (Raymond, 2015). This could also be related to the linear decreases in parental responsibility for diabetes tasks that have been found to correlate with deterioration in adherence, especially when adolescents did not report concomitant growth in self-efficacy (Wiebe et al., 2014).

Disease-Specific or Developmental-Specific Transitional Programs

A current literature review identified a limited range of interventions and studies, limited numbers of clinical conditions, and inadequate short-term follow up of the lengthy process of transition (Campbell et al., 2016) Another literature review of five transitional programs found inconsistent outcomes of present transitional programs (Chu et al., 2015). Two programs found no statistically significant effects (Chu et al., 2015). Of the three transition programs that measured post-transfer HgbA1C, only one program demonstrated improved HgbA1C rates following transition (Chu et al., 2015). Short term benefits of the use of financial incentives in motivating adolescents with T1DM to maintain independent self-management behaviors but lacked any long-term benefits (Wong, 2017).

One study used the Transition Readiness Assessment Questionnaire (TRAQ) to measure outcomes of a quality improvement program developed to assist the adolescent with T1DM in transition of care. (Little et al., 2016). The questionnaire measured readiness for transition using five subscales, which include appointment keeping, tracking health issues, managing medications, talking with providers, and managing daily activities (Little et al., 2016). Findings

of this study indicated that the adolescents participating in the transition program still had difficulty with appointment keeping and tracking health issues but showed confidence in managing daily activities, talking with providers, and managing medications (Little et al., 2016).

One study to evaluate the effectiveness and outcomes of a structured transition program for emerging adults with T1DM identified a process in the journey of transition to independent self-management of T1DM (Egan et al., 2015) The process started with remembering the beginning of the journey, then followed with learning to balance blood glucose and prevent crises, integrating diabetes into their life outside of their home, taking over their care, experiencing conflict with parents, and realizing the difficulties of managing diabetes. The process continued with accepting diabetes, becoming confident in their ability to manage diabetes, showing responsibility, and staying on track (Egan et al., 2015). The authors also noted a final phase of transition of helping others through mentoring and showing compassion to others (Egan et al., 2015).

A study of these emerging adults may provide some hindsight in the needs of the adolescent with T1DM, however, further examination of facilitators and inhibitors within this process needs investigation. A study using retrospective data from adolescents participating in a diabetes transition program found that following transfer to adult healthcare, the adolescents with T1DM that were more likely to be lost in follow up care were most commonly found to be diagnosed with T1DM before the age of 12, adolescents using multiple dose injections of insulin versus insulin pump, adolescents with higher pre-transition HgbA1Cs, adolescents with poor pediatric follow up the year before transfer, and adolescents who did not engage in the diabetes transition clinic.

The Influence of Technology on Independent Self-Management

The influences of technology in the form of insulin delivery, glucose monitoring, and the use of telemedicine have been evaluated (Los et al., 2016). Despite the data that supports improvements in self-management during adolescent transition to independent self-management with the use of insulin pumps and continuous glucose monitoring technology (Los et al., 2016; Maiorino et al., 2014), prescription of these devices is restricted by prescribers and insurance carriers (Los et al., 2016). The use of telehealth to improve access to care of adolescents with T1DM needs further investigation but will also be dependent upon provider reimbursement for telehealth services (Los et al., 2016)

Parent and Adolescent Perspectives of Independent Self-Management of T1DM

Qualitative studies have studied adolescents' experiences living with T1DM and transitioning to independent self-management, and the needs of adolescents with chronic conditions during transitions to independent self-management (Bomba et al., 2017; Hansen & Jensen, 2017; Babler & Strickland, 2016; Babler & Strickland; 2015). One identified the impact of transitional awareness, the crucial change in relationship with health care providers and the partnership with shared-decision making as important factors identified by adolescents in transition to independent self-management of T1DM (Hansen & Jensen, 2017). A theoretical model of adolescents with T1DM transitioning, "Normalizing" - the "ability of the adolescents to integrate diabetes into the background of their daily life by creating routines to make diabetes part of me" was proposed by Babler and Strickland (2016; 2015). During normalizing, the adolescent realizes that, though difficult, diabetes can be managed, and glucose control can be maintained independently of parent involvement.

A study of adolescents with chronic diseases found peer support, future and vocational issues, disease knowledge, transfer to adult medicine, changes in doctor-patient relationship, detachment from parents, the adolescent's health management and health system, implementation and methods of transition training, patient education programs promoting, adolescent self-management and empowerment increase preparedness for transition (Bomba et al., 2017). They concluded that adolescents would benefit from opportunities to exchange ideas and more specific information with peers about vocational and medical issues regarding adolescent health (Bomba et al., 2017) Common denominators of these studies were the relationships of the adolescents with parents, peers and healthcare providers.

Facilitators and Inhibitors of Independent Self-Management of the Adolescent with T1DM

This literature review identified *several conditions*-facilitators and inhibitors of independent self-management (Table 2). Psychosocial, psychological and economic transition conditions are foundational to success of the transition of the adolescent with T1DM to independent self-management. The healthcare provider and parents' perspectives of the transition of adolescents with T1DM to adult health care predominated this literature review.

TABLE 2. *Facilitators (F) and inhibitors (I) of independent self-management of the adolescent with type 1 diabetes in current literature*.

Author/Title	Facilitators and Inhibitors
Babler & Strickland (2015) Helping adolescents with diabetes "Figure it out."	F: Poor outcomes of poor self-management; feeling healthy when taking insulin; improved coping; positive outlooks; communication with peers; confidence; self-motivation; accepting help from others I: Denial of diabetes; hiding the disease from friends; embarrassment over disease
Babler & Strickland (2016) Moving the journey towards independence: Adolescents transitioning to successful diabetes self-management	F: Parental trust, parental monitoring; parental assistance; communication with parents; adolescent skill mastery; older age at transition; emotional preparedness; understanding of parental concern I: Younger age at transition; lack of knowledge; fear of injections; over-bearing/nagging parents; lying; burnout; a perceived difference from peers
Beal, Riddle, Kichler, Duncan, Houchen et al., (2016) The associations of chronic condition type and individual characteristics with the transition	F: Confidence; positive perceptions of healthcare; responsibility toward healthcare; higher psychosocial level/skills; higher developmental level; skill mastery; increased communication about the healthcare transition; older adolescent age at transition; residing in a two-parent home; higher health literacy I: Impairments in executive function; behavior or cognitive impairment; lack of anticipatory guidance
Bomba, Herrmann-Garitz, Schmidt, Schmidt, & Thyen, (2017) An assessment of the experiences and needs of adolescents with chronic conditions in transitional care: a qualitative study to develop a patient education program	F: Higher developmental level and psychosocial skills; communication with and between healthcare providers; peer support; increased disease knowledge I: Stress and anxiety; uncertainty of future and vocational issues; uncertainty of the process of transfer to adult medicine; changes in doctor-patient relationship; lack of age-appropriate communication with providers; detachment from parents
Campbell, Biggs, Aldiss, O'Neill, Clowes et al., (2016) Transition of care for adolescents from pediatric services to adult health services	F: Transitional programs that increase knowledge and self-efficacy. No firm conclusions on the effectiveness of transition programs due to short term follow up.
Carlsen, Skrivarhaug, Thue, Cooper, & Goransson et al. (2017) Glycemic control and complications in patients with type 1 diabetes-a registry-based longitudinal study of adolescents and young adults	F: Older age of adolescent at the time of transition; female gender I: Younger age at the time of transition; male gender

TABLE 2 – *Continued*

Author/Title	Facilitators and Inhibitors
Castensøe-Seidenfaden, Teilmann, Kensing, Hommel, & Olsen et al., (2016) Isolated thoughts and feelings and unsolved concerns: adolescents' and parents' perspectives on living with type 1 diabetes- a qualitative study using visual storytelling	F: Appropriate/individualized timing of transition of responsibilities; achieving developmental milestones; psychological well-being, higher quality of life; strong relationships with parents; good communication with healthcare providers I: Puberty; poor communication with parents; fear of hypoglycemia; feeling different; fear of the future; poor communication with parents, peers and healthcare providers; feeling different; parental concern over adolescent's competence
Chu, Maslow, von Isenberg, & Chung, (2015) Systematic review of the impact of transition interventions for adolescents with chronic illness on transfer from pediatric to adult healthcare	Pediatric to adult transition programs showed mixed outcomes of efficacy, quality, and success of transitional programs
Egan, Corrigan, & Shurpin (2015) Building the bridge from pediatric to adult diabetes care: making the connection.	F: Introduction of transition during early adolescence; formal transition processes; awareness of transition; parental and healthcare providers engagement in the transition process
Ersig, Tsalikian, Coffey, & Williams (2016) Stressors in teens with type 1 diabetes and their parents: Immediate and long-term implications for transition to self-management.	F: Use of parents and other family members and peers as resources; use of healthcare providers and clinic staff as resources; extended insurance coverage and access to resources I: Ineffective self-management; nagging from parents; fear of short and long-term outcomes; inappropriate timing and planning of transition; lower developmental level; parental fear of health consequences of transitioning responsibility (death); low parental confidence and trust in the adolescent with T1DM; health insurance changes
Farrell, Fernandez, Salamonson, Griffiths, & Holmes-Walker (2018) Health outcomes for youth with type 1 diabetes at 18 months and 30 months post transition from pediatric to adult care	F: Continued engagement with the multidisciplinary healthcare team

TABLE 2 – *Continued*

Author/Title	Facilitators and Inhibitors
Fernandez, S. M., O'Sullivan-Oliveira, J., Landzberg, M. J, Khairy, P., Melvin, P. et al. (2014) Transitioning and transfer of adolescents and young adults with pediatric-onset chronic disease: The patient and parent perspective.	F: Education about and knowledge of disease and treatment; pediatric provider as resource and mediator between pediatric and adult healthcare; older age at transfer; transitional support groups; allowing the adolescent to participate in transitional planning; a structured transitional plan I: Lack of education; emotional attachment to pediatric providers; perceived lack of providers; parents feeling excluded; perceived lack of providers, lack of specialty and internal medicine adult providers
Hagger, Hendrieckx, Sturt, Skinner, & Speight (2016) Diabetes distress among adolescents with type 1 diabetes: A systematic review	F: Cognitive restructuring; goal setting, problem-solving I: Diabetes distress; use of adult measurement tools in evaluating for DD
Hansen & Jensen (2017) Partnership in transition: Experiences of adolescents with type 1 diabetes	F: Transfer expectation at predetermined age; adolescents' preference for transition timing; increased adolescent autonomous behavior; health literacy and communication skills, provider knowledge of adolescent development; provider interest in and respect of adolescent's lifestyle; provider competence; provider conducting a relationship based on adolescent's preference I: Immaturity of the adolescent; unawareness of transition process; increased dependence on parents; provider conflict between evidence-based care and adolescent's right to direct care; lack of intimate patient knowledge by an adult healthcare provider
Helgeson, Reynolds, Siminerio, Becker, & Escobar (2014) Cognitive adaptation theory as a predictor of adjustment to emerging adulthood for youth with and without type 1 diabetes	F: Older age at transition; high self-esteem; high levels of skill mastery; high levels of optimism; self-control; association of own behavior with health outcomes; romantic relationships; supportive peer relationship I: Low self-esteem; a low sense of personal control; low optimism
Hilliard, Perlus, Clark, Haynie, Plotnick et al. (2014) Perspectives from before and after the pediatric to adult care transition: A mixed-methods study in type 1 diabetes.	F: Older age at transition; practice of self-management skills; independence, autonomy, feeling respected; ability to coordinate own healthcare; parental involvement; use of parents as safety nets; parental reminders; establishing safety net away from home; early preparation for transition; communication and overlapping visits with pediatric and adult healthcare providers; pediatric referral to adult providers; information sharing between providers; peer support I: Decreased access to parental support; fear of negative interactions with adult healthcare providers; parents delay of transfer; parental apprehension over ending the relationship with the pediatric provider; competing priorities between pediatric and adult healthcare providers; brief visits and impersonal interactions with providers; adult providers unawareness of transitional guidelines

TABLE 2 – *Continued*

Author/Title	Facilitators and Inhibitors
Joley, (2016) Integrating transition theory and bioecological theory: a theoretical perspective for nurses supporting the transition to adulthood for young people with medical complexity	F: Proper timing, the setting of realistic goals; advanced development level; dependency on microsystem; access to resources; healthcare providers' understanding of present goals
Joly, (2015) Transition to adulthood for young people with medical complexity: An integrative literature review	F: Knowledge and understanding, of transition; trust in adolescent; support and access to resources; peer support; coordination and preparation of and respect for the adolescent with T1DM by healthcare community; advocacy by providers; provider knowledge
Kapellen, Müther, Schwandt, Grulich-Henn, Schenk et al. (2018) Transition to adult diabetes care in Germany- High risk for acute complications and declining metabolic control during the transition phase	F: Insulin pump use I: Delayed or prolonged transition from pediatric to adult healthcare
Little, Odiaga, & Minutti (2016) Implementation of a diabetes transition of care program	F: Transition planning starting early in adolescence
Los, Ulrich, Guttman-Bauman (2016) Technology use in transition-age patients with type 1 diabetes	F: Online assessment tools; web-based transition programs; video conferencing; insulin pump and CGM devices; multiple provider collaboration; broader insurance coverage I: Developmental changes; anxiety; depression; mood and adjustment disorders; poor metabolic control; alterations in the parent-child relationship; differences in the adult health care setting; provider time constraints; lack of standardized transitional processes; lack of reimbursement for telemedicine
Lyons, Becker, & Helgeson (2014) Transfer from pediatric to adult healthcare: effects on diabetes outcomes	F: Female gender; physical and psychosocial maturation with older age; pediatric to adult healthcare transitional programs I: Early transfer from pediatric to adult healthcare system before the senior year of high school.
Maiorino, Bellastella, Petrizzo, Improta, Brancario, et al. (2014) Treatment satisfaction and glycemic control in young type 1 diabetic patients in transition from pediatric health care: CSII versus MDI.	F: CSII showed similar efficacy in reducing HbA1c compared with MDI, with less hypoglycemia and glycemic excursions, and was better in improving overall treatment satisfaction and the rate of perceived hyperglycemia and hypoglycemia
Mistry, Van Blyderveen, Punthakee, & Grant (2015) Condition-related predictors of successful transition from pediatric to adult care among adolescents with type 1 diabetes	F: Greater frequency of pediatric appointments; patients that ask more questions of their diabetes; transition appointments; lower HgbA1C; insulin pump use I: Diabetes diagnosis < 12 years of age; increased HgbA1C levels

TABLE 2 – *Continued*

Author/Title	Facilitators and Inhibitors
Polfuss, Babler, Bush & Sawin (2015) Family perspectives of components of diabetes transition program	F: Adolescent self-confidence; communication with providers;program-specific materials; parental education materials; transition classes; regular clinic attendance; individual visits with the nurse clinician; increased self-efficacy I: Incongruence between adolescent and parents' perception of the importance of behaviors needed for transition; conflict between parents, providers, and adolescents.
Quinn, Ambrosino, Doyle, Weyman, Tamborlane et al. (2016) Utility of psychological screening of young adults with type 1 diabetes transitioning to adult providers	F: formal screening to detect psychological problems
Raymond (2015) Updates in behavioral and psychosocial literature in adolescents with type 1 diabetes	I: Behavioral and psychosocial issues
Rollo, Salardi, Ciavarella, Forlani, Scipione et al. (2014) Transition from pediatric to adult care. Eight years after the transition from pediatric to adult diabetes care: Metabolic control, complications and associated diseases.	F: Regular pediatric care; older age at transition I: Psychiatric co-morbidity; poor metabolic control at the transition
Sawicki, Garvey, Toomey, Williams, Hargraves et al. (2017) Preparation for transition to adult care among Medicaid-insured adolescents	F: Identification of transition preparation I: Lower income; discussions not being initiated by healthcare providers regarding transition planning
Schmidt, Herrmann-Garitz, Bomba, & Thyen (2016) A multicenter prospective quasi-experimental study on the impact of a transition-oriented generic patient education program on health service participation and quality of life in adolescents and young adults	F: Disease-specific patient education transition program tailored to adolescents with chronic conditions Developmental adjustment of transitional planning, to adolescents age, 15-21 with an open frame to participate

TABLE 2 – *Continued*

Author/Title	Facilitators and Inhibitors
Sheehan, While, & Coyne (2014) The experiences and impact of transition from child to adult healthcare services for young people with type 1 diabetes: A systematic review	F: Continuity of care; lower HgbA1C at transition; structured educational programs and preparation for enhanced responsibility; automatic scheduling of follow up appointments; introduction to adult healthcare staff before transfer; advanced receipt of information; a collaboration between pediatric and adult healthcare providers; increased flexibility and frequency of appointments I: Decreased clinic attendance; lack of referral or receipt of adult providers' name; competing life priorities; difficulty getting an appointment; absent parent; history of abuse or neglect; substance abuse; being a parent or caregiver; cultural shift to adult care; younger age at T1DM diagnosis; parental disengagement at adult healthcare appointments; pediatric uncertainty of adult healthcare services needed t prepare adolescents for transition
Sullivan-Bolyai, Bova, Johnson, Cullen, Jaffarian et al. (2014) Engaging teens and parents in collaborative practice	F: Less focus on "numbers" by healthcare providers I: Pressure on parents by healthcare providers to manage teens' diabetes, scheduling appointment changes; long waiting times for appointments
White, O'Connell, & Cameron (2015) Transition to adult endocrine services: What is achievable? The diabetes perspective	F: older age I: Poor clinic attendance and follow up; higher HgbA1C; mental health disorders
Wiebe, Chow, Palmer, Butner, & Butler (2014) Developmental processes associated with longitudinal declines in parental responsibility and adherence to type 1 diabetes management across adolescence	F: Titration of adolescents' independence to their changing self-efficacy beliefs; increased adolescent self-efficacy; increased pubertal maturation I: Declines in parental responsibility without growth in adolescent self-efficacy
Wong (2017) Effect of financial incentives on glucose monitoring adherence and glycemic control among adolescents and young adults with type 1 diabetes	F: Financial incentives

Psychosocial Facilitators and Inhibitors of Independent Self-Management of the Adolescent with T1DM

The psychosocial support system of the adolescent with T1DM consists of parents, peers and healthcare providers, all of which may serve as facilitators or inhibitors of independent self-management. A framework of positive communication sustains relationships between the members of the adolescent with T1DM's support system, reduces conflict, builds trust, and is essential for glycemic control, and disease management (Bomba et al., 2017; Egan et al., 2015; Babler & Strickland, 2015; Joly, 2015; Hilliard et al., 2014; Rollo et al., 2014; Sheehan et al., 2014; Sullivan-Bolyai et al., 2014).

Parents. It is difficult for parents to negotiate the shift from the primary caregiver to supplemental resource necessary for their adolescent child with T1DM to transition to independent disease management. (Babler & Strickland, 2016; Polfuss et al., 2015; Sheehan et al., 2014; Sullivan-Bolyai et al., 2014). For example, parents may lack confidence in the ability of the adolescent with T1DM to anticipate short and long-term outcomes of their management decisions, which results in fear of adverse health consequences such as hypoglycemia and death (Ersig et al., 2016; Polfuss et al., 2015; Sheehan et al., 2014; Sullivan-Bolyai et al., 2014; Lyons et al., 2014). Further, parents must balance the desire to relinquish T1DM management responsibility to the adolescent while fearing being perceived as or judged by healthcare providers for being neglectful or uninvolved (Sullivan-Bolyai et al., 2014).

Adolescents and their parents experience the transition process differently, and therefore perceptions of success may differ (Joley, 2015). “Nagging” or overbearing parents or conversely parents that feel excluded from the management of their adolescent’s care may lack the

confidence in the adolescent with T1DM to manage their disease (Castensøe-Seidenfaden et al., 2016; Babler & Strickland, 2015; Fernandes, O'Sullivan-Oliveira, Landzberg, Khairy, Melvin et al., 2014; Hilliard et al., 2014). Parents may interfere with the adolescent's motivation to become independent with T1DM self-management, which can delay the transition process to adult health care (Castensøe-Seidenfaden et al., 2016; Babler & Strickland, 2015; Fernandes et al., 2014; Hilliard et al., 2014). Transitional program research and development should address the emotional responses of the parent on the diagnosis and treatment of T1DM and the impact of their responses such as nagging, on the adolescent (Babler & Strickland, 2015).

Parents who withdraw too early from assisted diabetes self-management may inhibit the transition of the adolescent with T1DM to independent self-management (Hilliard et al., 2014; Sheehan et al., 2014). Upon turning 18 years old, the adolescent with T1DM must provide consent to allow continued parental access to their medical records. Without access to care of the adolescent with T1DM, parents become disengaged from the adult health care system, which may increase psychological and psychosocial detachment from the adolescent with T1DM and impede a smooth transition of the adolescent with T1DM to independent self-management (Bomba et al., 2017).

Support and guidance of the relationship between the adolescent with T1DM and their parents, disease management education of the adolescent with T1DM, and integration of the adolescent with T1DM in the transition process may facilitate smoother transitions (Babler & Strickland, 2015; Joly, 2015; White et al., 2015). The role of the nurse is to provide disease etiology and management education and establish an equal partnership with the adolescent with T1DM in the transition process (Babler & Strickland, 2015; Joley, 2015; White et al., 2015).

Decreasing physical, psychological and psychosocial conflict between the parents and the adolescent with T1DM during the transition to independent self-management improves health outcomes (Babler & Strickland, 2016; Joly, 2015; White et al., 2015).

Peers. Although parental support has been found to have the most influence on the independent self-management of adolescents with T1DM, peer support groups are also important facilitators and inhibitors of independent self-management (Joley, 2015; Babler & Strickland, 2015). The adolescent with T1DM has two peer groups- those with and those without T1DM. Some adolescents have reported hiding their T1DM diagnosis from their peers due to embarrassment over disease processes and management requirements, which may limit friendships and influence their development of intimacy (Babler & Strickland, 2015; Lyons et al., 2014). Witnessing disease progression in peers with T1DM is sometimes distressful, but the guidance of those who have experienced the transition to independent self-management may also serve as a positive influence in the adolescent with T1DM transition (Bomba et al., 2017; Hilliard et al., 2014).

Healthcare providers. Engagement and follow-up care with the pediatric health care system before and during the transitional process predicts engagement and healthcare follow-up with the adult health care system (Mistry et al., 2015; White et al., 2015). Behaviors associated with poor long-term health care outcomes, such as lack of motivation for self-management or withdraw from support systems, may be difficult to correct following the transition to adult healthcare, so adherence to the standards of pediatric protocols for diabetes follow-up care lays the groundwork for long-term glycemic control (Farrell et al., 2018; Joley, 2016; Polfuss et al., 2015; Sheehan et al., 2014). Self-care behaviors such as scheduling, attending, and arranging

transportation to regular health care appointments, notifying healthcare providers of changes in health, navigating through the health care system and maintaining health insurance coverage, and managing the costs associated with maintaining health and well-being can provide insight into the causes of increasing HgbA1C levels (Farrell et al., 2018; Little et al., 2016).

Both adult and pediatric healthcare providers play a part in the smooth transition of the adolescent with T1DM to adult healthcare. Adolescents may lack preparation by the pediatric provider for the adult healthcare setting and develop an uncertainty or fear of the adult healthcare environment (Sawicki et al., 2017; Sheehan et al., 2014). The adolescent naïve to navigating through the adult health care system may have trouble scheduling appointments (Bomba et al., 2017; Fernandes et al., 2014; Sullivan-Bolyai et al., 2014). Adolescents with T1DM have further difficulties accessing healthcare due to shortages of adult providers that result in longer wait times between appointments (Bomba et al., 2017; Fernandes et al., 2014; Sullivan-Bolyai et al., 2014).

Adult health care providers may lack age-appropriate communication skills, and knowledge of the unique transitional needs of the adolescent with T1DM, so the adolescent with T1DM may perceive the adult healthcare system as impersonal (Bomba et al., 2017; Hansen & Jensen, 2017; Hilliard et al., 2014). Use of online integrated health records accessible to pediatric and adult healthcare providers involved in the transition of the adolescent with T1DM can contribute to improved communication amongst healthcare providers (Los et al., 2016). Online health literacy tools, telemedicine and video conferencing are methods that can improve adolescent and parent access to resources necessary for T1DM management and transition information (Los et al., 2016). For example, adolescents with T1DM who are limited in access to

healthcare professionals may be able to download data from technological devices, such as their continuous glucometers (CGM), and this data can be then uploaded by the healthcare professional for review (Los et al. 2016).

Early transfer to an adult healthcare system that the adolescent with T1DM perceives as stoic and detached may inhibit independent self-management (Kapellen et al., 2018; Lyons et al., 2014). However, a delayed transition may also impede independent self-management (Kapellen et al., 2018; Lyons et al., 2014). Healthcare providers must create a balance between guidance of the adolescent in the performance of independent self-management and recognition of the interdependence of independent self-management of the adolescent with T1DM (Sullivan-Bolyai et al., 2014).

Psychological Facilitators and Inhibitors of Independent Self-Management of the Adolescent with T1DM

Diabetes distress, depression, and eating disorders are common psychosocial comorbidities associated with poor glycemic control and poor health outcomes (Quinn et al., 2016; White et al., 2015; Rollo et al., 2014). The adolescent with T1DM who has poor self-esteem and a lower quality of life may revert to high-risk behaviors that further impair T1DM self-management (Castensøe-Seidenfaden et al., 2016; Babler & Strickland, 2015; Helgeson et al., 2014; Rollo et al., 2014). The age at which the adolescent with T1DM transitions to independent self-management varies, and is dependent on many physical, psychological and psychosocial factors (Beal et al., 2016; Babler & Strickland, 2015; White et al., 2015). Throughout the transition to adult health care, it is imperative to address the adolescent's

emotional state, coping levels, fears, and plans for crisis prevention, such as sick day management (Babler & Strickland, 2015).

Economic Facilitators and Inhibitors of Independent Self-Management of the Adolescent with T1DM

Part of transition to independent self-management of the adolescent with T1DM includes the preparation for relocation and leaving their family's home. Several studies have associated geographical relocation, and emotional and financial instability with higher amounts of psychological distress and deteriorating glycemic control (Quinn et al., 2016; Castensøe-Seidenfaden et al., 2016; Sheehan et al., 2014; Helgeson et al., 2014; Rollo et al., 2014). Uncertainties and changes in health care insurance and decreased access to disease management resources potentiates alterations in financial stability associated with moving out of the family home (Hagger et al., 2016; Adal, Onal, Ersen, Yalcin, Onal, et al., 2015; Raymond, 2015; Wiebe et al., 2014).

Gaps in the Literature

The gaps in current literature must be addressed to cultivate a clearer and deeper understanding of the facilitators and inhibitors of independent self-management of T1DM by adolescents. Gaps in current research include : 1) the influence of hormonal changes, insulin resistance, neurological and neurocognitive effects of type 1 diabetes, and psychological behaviors of the adolescent that impacts T1DM self-management (Polfuss et al., 2015); 2) the reasons adolescents with T1DM are unable to stay on track with the responsibilities of self-management, such as maintaining a healthy diet (Babler & Strickland, 2015); 3) the internal and external motivators such as financial and social incentives and technology, of independent self-

management (Los et al., 2016; Babler, 2015; Sheehan et al., 2014); 4) the mental health needs of the adolescent including diabetes distress and feelings of isolation during the transition process, as well as the sustainability of effect of cognitive restructuring, goal setting and problem solving on diabetes distress reduction (Hagger et al., 2016; Babler & Strickland, 2015); 5) the relationships and interdependence between the adolescent, parent, and providers (Castensøe-Seidenfaden et al., 2016; Polfuss et al., 2015; Sullivan-Bolyai et al., 2014); 6) adolescent, parental and provider knowledge of transition planning (Sawicki et al., 2017); 7) parental responses to the transition of their adolescent (Babler & Strickland, 2016); 8) and the support needs of adolescents with T1DM within their communities.

A single study cannot address this wide gap in knowledge. However, also evident in the findings of this literature search was the limited studies that solely focused on the adolescent perspective of facilitators and inhibitors of independent self-management of T1DM (Bomba et al., 2017; Hansen & Jensen, 2017; Babler & Strickland, 2016; Babler & Strickland; 2015). Most of the current research focuses on the perspectives of parents and healthcare providers of independent self-management of the adolescent with T1DM. This qualitative study was proposed to 1) build on current knowledge of the facilitators and inhibitors of independent self-management to understand the unique perspective of the adolescent with T1DM, 2) provide deeper insight on the facilitators and inhibitors of independent self-management to fill the gaps of knowledge in current literature, and 3) contribute new knowledge for the development of nursing transition programs that assist adolescents with T1DM in a smooth transition from the pediatric to adult healthcare settings.

Theoretical Framework

Meleis' transition theory (Figure 1) guided this study of the facilitators and inhibitors of independent self-management of the adolescent with T1DM. Transition is "a passage from one fairly stable state to another fairly stable state and it is a process triggered by change" (Meleis, 2010, p. 11). The concepts of a theory of transition of the adolescent with T1DM to independent self-management (Figure 2) may be adapted from transitions theory to include the nature of transitions, the facilitators and inhibitors of transitions, the patterns of knowing and the nursing interventions that facilitate transition (Meleis, 2010). The nature of transitions outlines the types, patterns, and properties of transition (Meleis, 2010). The transition conditions identify the personal meanings, cultural beliefs, socioeconomic status and the preparation and knowledge and their community and societal interdependence as facilitators and inhibitors of transition (Meleis, 2010). The patterns of response are the process and outcome indicators of transition (Meleis, 2010). Nursing therapeutics can facilitate transition at all levels of transition (Meleis, 2010).

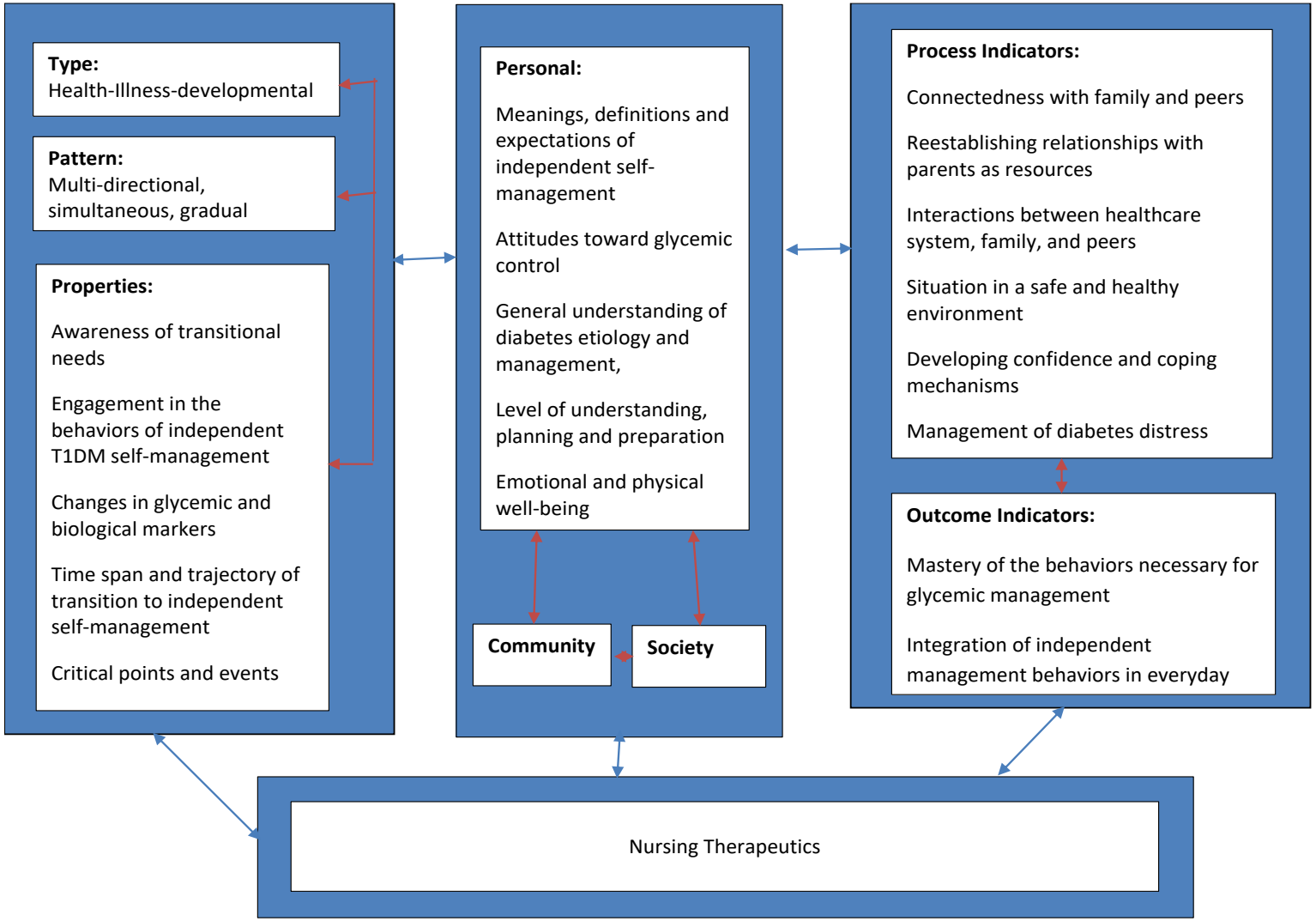


FIGURE 2. Preliminary proposed theory of transition of the adolescent with T1DM to independent self-management.

Nature of Transitions of the Adolescent with T1DM

The adolescent with T1DM experiences a health-illness transition that maintains a multidirectional relationship with the developmental changes of adolescence. The health-illness transition of the adolescent with T1DM from dependent to independent self-management of T1DM occurs in a single, gradual, sequential pattern. However, since the growth and development of the adolescent with T1DM is affected by hormonal effects of T1DM and puberty, the health-illness transition conditions, facilitators and inhibitors of the transition are interdependent with the developmental changes of adolescence. This is evidenced by current studies of transitional programs in adolescents with multiple chronic diseases, which highlight disease-specific variations in responses to transition (Wong, 2017; Campbell et al., 2016; Chu et al., 2015; Egan et al., 2015; Little et al., 2016; Mistry et al., 2015; Los et al., 2016; Maiorino et al., 2014). This chapter proposes an additional nature of transition specific to the adolescent with T1DM: A developmental-health-illness transition to independent self-management.

Health-Illness Transition of the Adolescent with T1DM

During all the stages of adolescence, the biological processes of chronic illnesses such as T1DM impacts biological, psychological, behavioral and social growth and development (Quittner, Romero, Kimberg, Blackwell, & Cruz et al., 2011). Conversely, adolescent behavior affects disease management and outcomes (Quittner et al., 2011). A diagnosis of T1DM during this time can significantly affect the adolescent's future health and well-being (Colombini & Schivalocchi, 2013).

Individual and environmental variables and the interplay between these variables influence health-illness transitions (Chick & Meleis, 2010). The meanings of transition, such as

how the adolescent defines independent self-management of T1DM, as well as the expectations of independent self-management during and after transitioning to adult healthcare, are conditions- individual and environmental variables that influence the transition process (Schumaker & Meleis, 2010; Chick & Meleis, 2010). Other conditions include the individual's level of knowledge and skill, such as understanding of diabetes etiology and management, level of planning and preparation for the transition, and emotional and physical well-being (Schumaker & Meleis, 2010; Chick & Meleis, 2010).

The hormonal changes throughout adolescence are complex. Hormonal regulation signaled by the hypothalamus causes changes in the brain that occur even before visible, physical changes in the adolescent develop (Brown et al., 2005; Salmela-Aro, 2011; Wright & Kutcher, 2016). Thyroid hormones that are essential for healthy growth and development for regulation of protein metabolism and sex hormones such as adrenal androgens and estrogen manage bone growth, nutrition and weight (Brown et al., 2005). Hormonal imbalances and abnormalities impair healthy growth and development (Faienza, 2017).

Suppression of the hormonal changes of adolescence due to chronic illness can lead to delayed puberty and short stature (Quittner et al., 2011). Decreased levels of insulin and growth hormone accompanied by chronic hyperglycemia and accumulation of end-products that result from protein and glucose metabolism result in suppression of bone formation and shorter stature (Faienza, 2017). With the predominance of co-morbid autoimmune diseases in adolescents with T1DM, the risk for nutritional imbalance, gastrointestinal disruptions, glycemic variation and long-term complications of short-stature and decreased bone density are magnified (Mackinder, Allison, Svolos, Buchanan, Johnston et al., 2014; Gopee et al., 2013). Bone loss can occur

shortly after diagnosis of T1DM leading to bone fragility due to diminished osteoblast function (Faienza, 2017). However, the exact mechanisms that inhibit bone growth in individuals with T1DM are not entirely understood, and data that support the long-term effect of glycemic control on bone growth is conflicting (Faienza, 2017).

Despite advanced technologies and intensive insulin therapies, adolescents with poorly controlled T1DM remain at higher risk for shorter stature (Bonfig, Kapellen, Dost, Fritsch, Roher et al. 2011). Consequences of glycemic control on bone growth are evident in the correlation between growth and final adult height (Faienza, 2017; Bonfig et al., 2011). Conversely, linear growth charts and final adult height may be indicators of metabolic control (Faienza, 2017; Bonfig et al., 2011).

The endocrine and immune system have a multidirectional relationship, which plays a role in both the onset and outcome of T1DM. For example, glucocorticoids play a part in repression and resolution of inflammatory processes (Daruna, 2017). This process can affect almost every cell of the body or target specific cell populations, which prevent hyperactivation of the immune system and ensure homeostasis (Daruna, 2012).

The impact and duration of the inflammatory response depend upon the bidirectional relationship between the innate and adaptive immune systems (Daruna, 2012). Errors in any phase of the immune response can lead to autoimmune diseases, such as T1DM (Daruna, 2012). Errors in the immune response also lead to the development of co-morbid autoimmune diseases in individuals with T1DM (Daruna, 2012).

Health-Illness-Developmental Transition of the Adolescent with Type 1 Diabetes

It is fruitless to ascribe age ranges to stages of adolescent development. *Erikson's Psychological Model of Personality* ascribes age ranges to the adolescent's development of identity influenced by past achievements and failures (Dunkel & Harbke, 2017). Research studies have examined the transition of the adolescent with T1DM to adult healthcare and have found a discrepancy between age and transition- readiness - for some it may be at age 16 years, whereas others are not ready until age 20 (Fegrenm, Hall, Uhrenfeldt, Aagaard, & Ludvigsen, 2014). Therefore, stage-oriented psychological and psychosocial changes and process-oriented changes of puberty and physiological growth are a better marker of the core features that separate adolescence from childhood, and readiness for independent disease self-management (Becht, Nelemans, Branje, Vollebergh, Koot et al., 2010; Brown et al., 2005). Some of these markers of readiness include hypothetical, multi-dimensional, relative and abstract thinking, and self-reflection during early, middle and late adolescence (Keating, 2011).

Early adolescents begin the development of self-identity and reflection on a new framework of personal values (Newman, & Newman, 2011; Becht et al., 2010; Brown et al., 2005). Early adolescence marks the beginning of the separation of self from family and the exploration of alternative relationships (Becht et al., 2010; Brown et al., 2005). The early adolescent realizes parental flaws and becomes less inclined to value their advice which results in engagement in risk-taking behavior (Brown, Strasburger, Coupey, Rogers, & Braverman, 2005). As the adolescent with T1DM experiences increasing familial conflicts, their adherence to their healthcare treatment plan decreases (Wasserman et al., 2017). Concrete thinking without thought of consequences increases the likelihood of risk-taking behaviors, unrealistic goal

setting, friction in relationships with authority figures and mood swings (Wasserman et al., 2017; Brown et al., 2005).

The adolescent questions their parents' value system, and mays find that it is no longer reflective of their own value system (Newman & Newman, 2011; Becht et al., 2010; Brown et al., 2005). The resulting conflicting value system that leads to disrupted relationships between the adolescent and their parent creates an emotional void (Newman & Newman, 2011; Becht et al., 2010; Brown et al., 2005). The adolescent then turns to peer relationships to fill this void (Newman & Newman, 2011; Becht et al., 2010; Brown et al., 2005).

The instant gratification of early adolescence evolves into feelings of immortality that leads to increased risk-taking behaviors (Brown et al., 2005). Increased risk-taking behaviors by adolescents with T1DM effect adherence to a health plan of care and disease self-management and has short- and long-term health consequences (Wasserman et al, 2017). For example, the adolescent with T1DM ashamed of the requirements of disease management may cut corners in carbohydrate counting when out with their peers, increasing the risk for excessive insulin administration and a hypoglycemic event.

Risk-taking behaviors common in adolescence such as binge drinking, unprotected sex, and reckless driving have increased health consequences for the adolescent with T1DM (Wasserman et al., 2017). Binge drinking increases the risk of hypoglycemic episodes in adolescents with T1DM (Monoghan, Helgeson, & Wiebe, 2015). Increased exposure of adolescents with T1DM to sexually transmitted challenges the immune system, making glycemic control more difficult (Thurheimer, Sereika, Founds, Downs, & Charron-Prochownik, 2016). In girls, there can also be a risk of reproduction health complications (Thurheimer et al., 2016).

Youth with diabetes are more likely than those without diabetes to smoke cigarettes (American Diabetes Association [ADA], 2018). For adolescents with T1DM, this can lead to microvascular and macrovascular complications, and albuminuria (ADA, 2018).

Creative reflection and forethought during middle adolescence allow for more realistic aspirations (Brown et al., 2005). As the adolescent reaches middle adolescence, bonds between peers and conformity with peer values become important, autonomy increases, and this results in conflicts with parents‘ and family values (Brown et al., 2005; Grant et al., 2011; Salmela-Aro, 2011). Body image emerges through a normative identity crisis as adolescents compare their physical development to that of peers and conflicting internal and external experiences, pressures, and expectations resolve (Wright & Kutcher, 2016; Grant et al., 2011; Becht et al., 2010; Brown et al., 2005). An intensified preoccupation with peer evaluations can have detrimental effects on adolescent body image and result in self-loathing (Harter, 2011). Alternatively, it can serve as a comfortable arena for introspection and self-evaluation as the adolescent compares personal growth to that of their peers (Salmela-Aro, 2011).

In addition to the pressure of body type stereotypes in the media, the adolescent with T1DM has increased pressure from parents and the healthcare community to focus on their bodies (Troncone, Cascella, Chianese, Galiero, & Zanfardino, 2018). The adolescent with T1DM has a greater understanding and awareness of the effects of the diagnosis of T1DM on their body and the relationship between T1DM and body shape and size (Troncone et al., 2018). As a result, compared to an adolescent without T1DM, adolescents with T1DM are at higher risk for body image disturbance such as underestimation of and dissatisfaction with body size and eating disorders (Troncone et al., 2018; Araia, Hendrieckx, Skinner, Pouwer, Speight et al., 2017).

Normative biological mechanisms, such as activities that activate the brain's dopaminergic reward system, and avoidance of situations deemed unpleasant, such as lying to a parent about checking their blood glucose levels to avoid being nagged, drives risk-taking behavior during adolescence (Wasserman et al., 2017). During middle adolescence, cognitive thinking vacillates between concrete and formal operations as the adolescent develops more abstract thought processes and reasoning ability (Brown et al., 2005). The social-reactive responses due to impulsivity and poor self-control results in novelty-seeking behavior in adolescence (Wasserman et al., 2017). The adolescent is more likely to weigh the cost and benefits of risky behaviors that an adult would never consider doing (Wasserman et al., 2017).

Difficulties in adjusting to new social roles may alter personality development in the adolescent with T1DM (Rassart, Oris, Prikken, Weets, Moons et al. 2018). During their search for a self-identity and new value system, the adolescent "self" differentiates as the adolescent adapts to various social environments (Harter, 2011). The adolescent explores new personas and carefully examines the community and societal views and reactions to these new personas (Harter, 2011). Thus, early adolescents gradually develop social cognition and the ability to recognize the nuances of social situations that require behavior modification (Wright & Kutcher, 2016).

The personality of the adolescent with T1DM affects their experiences of diabetes distress, glycemic control and treatment adherence (Rassart et al., 2018). For example, adolescents with T1DM who value peer assignment to avoid feeling different from their peers may not adhere to treatment guidelines (Rassart et al., 2018). Conversely, more agreeable or

conscientious adolescents with T1DM are more likely to adhere to treatment guidelines (Rassart et al., 2018).

Adolescents face fluctuations between certainty and uncertainty of individuality, self-determination, self-agency and the ability to take ownership of personal values while struggling to find acceptance and belonging (Wright & Kutcher, 2016; Newman & Newman, 2011; Becht et al., 2010). During identity formation, the adolescent challenges parental values that historically guided their behavior to this point in the adolescent's development.

The adolescent with T1DM's understanding of and motivation to adapt to new role behaviors during late adolescence impact their ability to perform the new role behaviors of independent self-management (Meleis, 2010). Decreased peer interactions and limitations in extracurricular activities due to the management of chronic illness also interferes with social development (Quittner et al., 2011). Support and guidance of the adolescent with T1DM and their parents, increasing knowledge of disease management of the adolescent with T1DM, and allowing the adolescent with T1DM to be an equal partner in the transition process may decrease conflicts during the transition to independent self-management (Babler & Strickland, 2016; Joly, 2015; White et al., 2015).

Adolescent growth and development and the etiology and management of T1DM are in a continuous tug of war within the adolescent with T1DM transitioning independent self-management. Puberty, rapid physical growth, and the resulting changes in body shape and brain development mark both a developmental stage of adolescence and health-illness transition in adolescents with T1DM (Wasserman et al., 2017; Columbini & Schivalocchi, 2013). Adolescents with T1DM transitioning to independent self-management have unique transitional

properties, conditions, facilitators and inhibitors and patterns of response that nursing interventions must address.

The properties of transition of adolescents with T1DM to independent self-management include awareness of transitional needs, engagement in the behaviors necessary for independent self-management of T1DM, changes in glycemic and biological markers such as HgbA1C, blood glucose logs, and microalbumin levels, the time span and trajectory of the transition to independent self-management, and critical points and events marking a transition (Meleis, 2010).

Transition Conditions: Facilitators and Inhibitors

The transition of the adolescent with T1DM from dependent disease management orchestrated by parents and healthcare providers, to independent self-management is dependent upon individual and environmental conditions (Meleis, 2010). These conditions include the adolescent with T1DM's definition and expectations of independent self-management, their general understanding of diabetes etiology and management, the level of planning and preparation for the transition, and emotional and physical well-being (Meleis, 2010; Chick & Meleis, 2010; Schumaker & Meleis, 2010). These conditions of transition occur during changes in the adolescent's social context and with attainment of new knowledge and experiences (Meleis, 2010; Chick & Meleis, 2010; Schumaker & Meleis, 2010).

Health-Illness Transitional Conditions of the Adolescent with T1DM

The poor glycemic control associated with adolescence correlates with decreasing psychological and social support, as well as psychiatric co-morbidities such as depression and anxiety (Adal et al., 2015; Johnson et al., 2013). Adolescents with T1DM are at risk for diabetes distress, depression, and anxiety which results from both genetic predisposition and

environmental influences and impacts cognitive functioning, and proper self-management practices (Salmela-Aro, 2011; Wright & Kutcher, 2016; Delamater, Patino-Fernandez, Smith, & Bubb, 2013; Johnson et al., 2013). Stress complicates the emotional turbulence of adolescence, which interferes with adaptation to the transitions of adolescence and psychological problems (Grant et al., 2011; Salmela-Aro, 2011). The events that moderate and mediate stressors at various times during adolescence varies on the level of reasoning, and coping skills developed by the adolescent with T1DM (Grant et al., 2011).

Forgetfulness, disorganization, adolescent anxiety, distress and depression, low self-efficacy, low self-concept, and exposure to bullying and stigmatization that results from a T1DM diagnosis influence the adolescent's mental health which makes reaching developmental milestones difficult (Kew, Carr, & Crossingham, 2017; Kim, Mazenga, Yu, Ahmed, Paul et al., 2017; Wang, Andrews, Gardner, Wood, & Singer et al. 2017; Novak, Stefan, Prosoli, Emeljanovas, Mieziene et al., 2017; DiBartolo, Nicolucci, Cherubini, Iafusco, & Scardapane et al., 2017; Guix-Comellas, Rozas, Velasco-Arnaiz, Morin-Fraile, & Force-Sanmartin et al., 2017; Chenneville, Machacek, St John Walsh, Emmanuel, & Rodriguez, 2017; Ferro & Boyle, 2012). Mediators of stress that weaken the adolescent's coping abilities such as restrictions in independence, confusion in identity formation, limitations in future aspirations and increased symptoms of depression or anxiety due to a chronic disease diagnosis interfere with healthy psychological development (Quittner et al., 2011). Immature cognitive development, body image sensitivity, hormonal changes, limitations in self-care skills, increased risk-taking behavior and perceptions of indestructibility interfere with T1DM self-management (Quittner et al., 2011).

Adolescents with T1DM that do not reach developmental milestones suffer disruptions in cognitive and emotional development which impact T1DM management adherence and increase the likelihood of risky health behaviors in chronically ill adolescents (Hanghoj & Boisen, 2014; Nylander, Seidel, & Tindberg, 2014). Research suggests that the devaluation of parental influences over peer influences characteristic of adolescent growth and development may lead to both poor transitions to independent self-management and adulthood, and poor physical and mental health outcomes in adolescents with T1DM (Quittner et al., 2011). Impaired relationships with parents, peers and providers, the overwhelming demands of treatments and medical complexity, and the cost of healthcare serve as inhibitors to proper health management of the adolescent with chronic illness (Kew et al, 2017; Kim et al.,2017; Wang et al., 2017; Novak et al., 2017; DiBartolo et al., 2017; Guix-Comellas et al., 2017; Hanghoj & Boisen, 2014; Tan, Bradley-Klug, & Chenneville, 2017).

Personal, community and societal conditions facilitate or inhibit individual transitions (Meleis, 2010). These conditions evolve from the individual's presence in and relationships within a community and society (Meleis & Sawyer et al., 2000). Adherence to the standards of pediatric protocols for diabetes follow-up care lays the groundwork for long-term glycemic control (Joley, 2016; Polfuss et al., 2015; Sheehan et al., 2014).

Health-Illness-Developmental Transition of the Adolescent with T1DM

Individual conditions such as the co-occurrence of rapid physical, psychosocial and psychological developmental changes of puberty, progressive brain development, and changes in T1DM etiology create health vulnerability of the adolescent with T1DM during transition to independent self-management (Bomba et al., 2017; Beal et al., 2016; Ersig et al., 2016;

Castensøe-Seidenfaden et al., 2016; Los et al., 2016; Babler & Strickland, 2015; Egan et al., 2015; Chu et al., 2015; White et al., 2015; Hilliard et al., 2014; Helgeson et al., 2014; Rollo et al. 2014; Sheehan et al., 2014). Alterations in adolescent physical growth and development then impact the ability of the adolescent with T1DM to perform the necessary behaviors of independent self-management (ADA, 2018). The impact of developmental level and age of the adolescent during transition to independent self-management not only effects health outcomes, but glycemic trajectories in adulthood as well (Carlsen et al., 2017; Bomba et al., 2017; Beal et al., 2016; Schmidt et al., 2016; Babler & Strickland, 2015; White et al., 2015; Sheehan et al., 2014; Lyons et al., 2014; Rollo et al., 2014; Hilliard et al., 2014; Helgeson et al., 2014; Fernandes et al., 2014).

The successful educational advancement of the adolescent follows a trajectory from high school to vocational schools, college, or the start of a career and perhaps a family (Brown et al., 2015). With the loss of parental supervision and moderation of risk-taking behaviors, non-adherent behaviors increase during late adolescence, and the adolescent with T1DM is vulnerable to poor health outcomes (Wasserman et al., 2017). However, with successful adolescent development, personal values and identities reconcile, relationships with family members improve, and intimate relationships replace peer group memberships (Brown et al., 2015; Grant et al., 2011; Salmela-Aro, 2011).

Transition conditions that facilitate or inhibit a developmental-health-illness transition include personal meanings of independent self-management, cultural beliefs, and attitudes toward glycemic control, socioeconomic factors, and the preparation and knowledge required for transition (Meleis, 2010). Adolescents may be stigmatized through the limitations and lack the

skills and experience to contribute to society (Flaskerud, Lesser, Dixon, Anderson, & Conde et al, 2002). Power differentials exist between adolescents and adults who further interfere with the adolescent's ability to gain knowledge to avoid health risk factors, minimize consequences and influence the process of their disease (Flaskerud & Lesser et al., 2002). The adolescent may also have a limited understanding of navigation of the healthcare and health insurance industries, which can affect the quality of healthcare received (Flaskerud & Lesser et al., 2002).

The conditions of transition of the adolescent with T1DM to independent self-management are dependent on a fine balance of support from the adolescent with T1DM's community (Meleis, 2010). This fine balance of support may be compromised changes in relationships with parents, family, peers and healthcare providers due to developmental changes as well as alterations in health status. The adolescent with T1DM must further integrate themselves into a larger society as they enter adulthood while carrying with them a T1DM diagnosis and the burdens of disease management.

Patterns of Response of the Adolescent with T1DM

Process indicators define the patterns of response to the transition of the adolescent with T1DM to independent self-management and include feelings of connectedness with peers and family, and re-establishing relationships with parents as resources of T1DM self-management (Meleis, 2010). Process indicators to resource attainment include interactions between healthcare providers, family and peers, and the situation in a safe and healthy environment that includes the provision of diabetic supplies, adequate nutrition, affordable health insurance and access to the healthcare system, developing confidence and coping mechanisms, and management of diabetes distress (Meleis, 2010). Outcome indicators include mastery of the behaviors necessary for

glycemic management and integration of these behaviors in everyday life (Meleis, 2010). Nursing therapeutics and interventions must be tailored to the developmental and health-illness transitions that are concomitantly occurring on variable trajectories.

Indicators of healthy transitions include the resolution of distress and the restoration of disrupted relationships during the transitional process (Schumaker & Meleis, 2010). Improved communication between the adolescent with T1DM, parents, and pediatric and adult healthcare providers involved in independent self-management transition can prevent disrupted healthcare follow up and poor health outcomes (Bomba et al., 2017; Egan et al., 2015; Jolly, 2015; Rollo et al., 2014; Hilliard et al., 2014; Sheehan et al., 2014; Kime, 2013; Lotstein, Seid, Klingensmith, Case, Lawrence et al., 2013; Lyons et al., 2014). Increased satisfaction of adolescents with T1DM with peer, parental and provider support during the transitional process may improve adherence to self-management practice and promote positive long-term outcomes (Maiorino et al., 2014).

Nursing Therapeutics to Assist the Adolescent with T1DM

Nurses must identify the indicators and outcomes of healthy transitions to facilitate research and evaluate interventions (Schumaker & Meleis, 2010). These indicators and outcomes include the subjective well-being of the adolescent with T1DM, mastery of the independent self-management role, and well-being of the relationships between the adolescent with T1DM and their parents, peers, and providers (Schumaker & Meleis, 2010). Insufficient knowledge and skill, poor access to resources, and physical and psychosocial stress serve as inhibitors that interfere with the assimilation of the new knowledge required and individual well-being during

transitions to independent self-management by the adolescent with T1DM (Schumaker & Meleis, 2010). Nursing therapeutics must facilitate resource attainment in the adolescent with T1DM.

Summary

Perceptions of healthy growth and development and the pathophysiological processes of T1DM contribute to the self-health assessments by the adolescent with T1DM. Conflicts may arise when health requisites of T1DM interfere with healthy growth and development. Many transitional conditions during adolescence may impact the self-management of the adolescent with T1DM. Developmentally appropriate nursing therapeutics and interventions may assist the adolescent with T1DM in a healthy transition to independent self-management.

Conclusion

Current research studies have identified multiple psychosocial, psychological, behavioral, emotional, physical and economic facilitators and inhibitors of successful transitions of the adolescent with T1DM to independent self-management and the adult health care system Yet, present transitional programs do not meet the transitional needs of adolescents with T1DM. This gap between current research and transition success may be better understood through research of the facilitators and inhibitors of independent self-management from the perspective of the adolescent with T1DM.

CHAPTER 3: METHODOLOGY

Research Design

Despite a robust literature set and transitional programs that have been implemented, adolescents with T1DM continue to be unsuccessful with transitioning from dependent to independent self-management. Further research that explores and identifies the facilitators and inhibitors of transition from dependent to independent self-management of the adolescent with T1DM, from their perspective, is needed to inform transitional interventions. The purpose of this qualitative descriptive study was 1) to cultivate a clearer and deeper understanding of the facilitators and inhibitors of independent self-management of T1DM by adolescents, 2) to elicit their perceptions of behaviors required for independent self-management and, 3) to identify resources used by this population to support independent self-management.

Research Questions

1. What are the self-management behavior skills required for the adolescent with T1DM during transition from dependent to independent T1DM self-management?
2. What facilitates everyday participation in self-management behaviors for adolescents with T1DM?
3. What are the barriers to participating in everyday self-management behaviors for adolescents with T1DM?

Study Method: Qualitative Description (QD) Methodology

A qualitative descriptive methodology was used to explore the adolescent's understanding of required self-management behavior skills, and their perception of the facilitators and inhibitors and resources used in everyday participation in independent T1DM

self-management behaviors. The overarching goal was to contribute new knowledge for the development of future nursing transition programs that assist adolescents in achieving independent T1DM self-management and a smooth transition from the pediatric to adult healthcare settings.

The qualitative description methodology is rooted in naturalism and relies on everyday language to describe a phenomenon (Sandelowski, 2010). It is interpretive, thematic and minimally theorized to allow for a naturalistic inquiry (Sandelowski, 2010). Qualitative description addresses the question of what a phenomenon is by summarizing an event within the environment in which the event takes place and identifies the who, what and where of events to identify knowledge gaps and support further research study (Sandelowski, 2000). For example, the research question in this qualitative description study, "What are the self-management behavior skills required for the adolescent with T1DM during the transition from dependent to independent T1DM self-management?" elicits a response that describes the what, why and how of the phenomena of independent self-management for the adolescent with T1DM.

The scientific world values prediction and control and facts discovered through quantitative methods; however, a quantitative design is limited in that it leaves little room for unexpected events within a naturalistic setting and makes conceptual meaning, and participant perception, inclination and sensitivities difficult to ascribe outside of the quantitatively studied context (Sandelowski, 2000). Clinical indicators of glycemic control such as HgbA1C or glucose monitoring may represent glucose control, but do not reflect the perception of what self-management constitutes to the adolescent with T1DM.

Qualitative data collection- fieldwork, participant observation and interviewing, describing, analyzing and interpreting data, provides an interpretive understanding of the social and cultural behavior of the adolescent with T1DM transitioning to independent self-management (Wolf, 2012). An understanding of the adolescent's perception of self-management behavior skills required for transitions from dependent to independent T1DM self-management and the facilitators and inhibitors to independent T1DM self-management is an important analytical step in our understanding the transition process (Wuest, 2012).

Sample and Setting

The goal of sampling in a qualitative descriptive study is maximum variation and to obtain a sample that can provide the richness of data needed to discover more about a phenomenon (Sandelowski, 2010). The use of a convenience sample in this study may imply a risk for limited representativeness of a study population; however, using a purposive sample and narrower focus of a study - such as this study on the facilitators and inhibitors of self-management of adolescents with T1DM, lowers the number of study participants required to reach data saturation- the point in which no new data are generated (Malterud, Siersma, & Guassora, 2015; Miles, Huberman, & Saldana, 2014). The use of a purposeful sample of adolescents with T1DM in this study is the hallmark of qualitative description design and provided information-rich details on the adolescents' perceptions of the facilitators and inhibitors of independent self-management (Sandelowski, 2010; Sandelowski, 2000; Loescher, Crist, & Siaki, 2009).

A total sample size of 11 adolescents with T1DM ensured data saturation and support for the applied theoretical basis of study and the analysis strategy (Malterud et al., 2015; Miles et al.,

2014). The sample for this study included five males and six female adolescents with T1DM. Most of the current qualitative studies achieved data saturation with sample sizes ranging from 9-29 (Hansen & Jensen, 2017; Herrmann-Garitz, 2017; Babler & Strickland, 2016; Castensøe-Seidenfaden et al., 2016; Ersig et al., 2016; Babler & Strickland, 2015; Sullivan-Bolyai et al., 2014). The emergence of themes from smaller samples of adolescents with T1DM stratified by gender facilitated the discovery of facilitators and inhibitors of the process of transition to independent T1DM self-management.

Inclusion and Exclusion Criteria

Criteria for inclusion in this study were: (1) adolescent females and males between the ages of 15 and 17, (2) diagnosed for at least one year with T1DM, (3) accepted into Camp Possibilities, (4) able to fluently speak, read and write in English, (5) and able to participate in one approximately 60-minute focus group consisting of members of their same sex. Criteria for exclusion was having a mental health condition that would limit participation and/or be disruptive in a 60-minute focus group (i.e., ADHD, autism, etc.).

Setting

The setting for this study was a campground that housed Camp Possibilities, a week-long summer residential camp leadership program for adolescents diagnosed with T1DM. The camp is located in Darlington, Maryland. The camp was originally developed for the purpose of providing children and adolescents diagnosed with T1DM to participate in a camp environment where otherwise they would be excluded due to their disease process. The camp has been conducted yearly for 13 years. Approximately 25 pediatric endocrinologists, nurse practitioners, registered nurses, certified diabetes educators, and registered dietitians volunteer as Camp

Possibilities healthcare staff every year. In addition, approximately 65 high school and college students and professionals from the community volunteer their services in counselor and recreation staff roles each year. Approximately 90 adolescents are accepted to camp every summer and the average number of adolescents between the ages of 15-17 years is 12, however, enrollment for this age group was 17 during the study. The cost of the camp is $775/camper with scholarship availability. On average 30% of all campers receive some form of financial assistance each year. Acceptance to camp is without regard to race, gender, or co-morbid medical or mental health conditions. Camp acceptance begins with an online application process monitored by the Camp Director. The healthcare staff and Camp Director scrutinize the motivations of the applicants for camp participation. The healthcare staff and Camp Director address any incompatibilities between motivations to attend and performance requirements of camp participation and develop accommodations for safe participation as needed. Camp Possibilities offers swimming, fishing, arts and crafts projects, basketball, field games, a nature walk, talent show, dance, and other activities. Dedicated diabetes education sessions provided by the interdisciplinary health care staff (i.e., pediatric endocrinologists, nurse practitioners, nurses, nutritionists, & diabetes educators) at camp are intended only in the spirit of providing support, information and encouragement to campers. Some of the most valuable educational opportunities come in the form of teachable moments, which occur when the campers interact with the healthcare staff and their counselors during insulin administration and throughout the day.

The camp environment provides physical, psychological, and psychosocial comfort and safety, encourages expression and communication of children and adolescents with T1DM, and protects the privacy of children and adolescents with T1DM. The primary investigator (PI) has

volunteered as a nurse practitioner (NP) at Camp Possibilities over the past 11 years. The PI has been active in the development of camp policy and procedures, including a behavior management program for campers with cognitive, behavioral or mental health co-morbidities. Additionally, the PI has been a participant in the planning and development of the adolescent leadership in training program. The camp environment thus facilitates rapport building in a relaxed open atmosphere between the PI and the participants, which is expected to contribute to the saturation of data (Thorne, 2016; Green & Thorogood, 2014).

Recruitment Procedures

A recruitment flyer that invited adolescents with T1DM to participate in the study was sent to the residence of adolescents and their guardian(s) who were accepted into the 2019 Camp Possibilities leadership in training program for 15-17-year old campers. The recruitment flyer, with the PI's contact information (e-mail address and cell phone number), was sent via U.S. mail one month before the summer camp began (Appendix E). The recruitment flyer included the purpose of the research study, what was asked of the adolescent if they participate in the study, and the length of time required to participate in the one-time focus group. The recruitment flyer and copy of assent/parental permission forms (Appendix A & B) were also attached to an email by the Camp Director one week following the mailing. The intention of the email was to coordinate camper arrivals and incorporate the assent/parental permission process in the camp sign-in schedule. Approval from the Camp Director was obtained to approach campers for recruitment purposes and to conduct a qualitative description study in the camp setting (Appendix F). Upon arrival, the adolescent/guardian dyads interested in learning more about the

study met with the PI after they signed in to camp. Those dyads that chose to participate met privately with the PI to obtain assent/parental permission

Human Subjects Protection Procedure

Approval was secured from the University of Arizona Institutional Review Board (IRB) (Appendix D) before initiation of this research study. Plans for confidentiality in data collection, storage, and analysis were explicitly evidenced. Specific ethical risks to adolescents with T1DM in this study were considered. Considerations began with the recruitment process, which included informed consent, risks, and benefits of participating in the study, and ethical considerations inherent to vulnerable populations, specifically children and adolescents (Miles et al., 2014). Informed assent and parental permission was obtained from both the adolescent with T1DM and their guardian as directed in the Belmont Report (1978) with special attention to the physiological and psychological ability of the adolescent with T1DM to understand and accept the details of informed consent for, and the risks and benefits of, participation.

The PI met with the potential participant and their guardian who expressed interest in the study during camp check-in to determine if they met inclusion criteria. The assent/parental permission forms were read to/with all participants and their guardian who met inclusion criteria and expressed interest in the study that met inclusion criteria. Upon completion of the review of the consent/assent forms, the PI asked the participant and their guardian to state the purpose of the study, who is conducting the study, what is being asked of them in the study, and ask if there are any risks in participating in the study. If either member of the dyad could not correctly answer these questions, the assent/parental permission forms were reviewed again until they were able to correctly respond to the questions. Participants and their guardians were provided a

copy of the consent form. Written assent/parental permission included the right of participants to voluntarily withdraw from the study at any time, the central purpose of study and procedures used for data collection, the protection of confidentiality of participants, the known risks associated with participation, and the expected benefits to accrue to the participants (Green & Thorogood, 2014). Before each focus group, participants were reminded of their right to withdraw from the study at any time without any impact on their ability to participate in camp activities. The guardians were provided the personal cell phone number of the PI for any questions/concerns. The participants had continued access to the PI throughout their week of camp participation.

Studies involving individuals as minors or high-risk sensitive populations require a thorough and possibly more detailed and lengthy review of proposal procedures, selection, sampling, and data collection strategy (Creswell & Poth, 2018). A focus group setting may pose risks to confidentiality of adolescents with T1DM with unique or high-risk needs. Although current studies have successfully used focus groups on adolescents with T1DM to inform transitional programs (Ersig et al., 2016; Freeborn, 2013), participants may still become uncomfortable or intimidated during interviews. The PI did not identify any occurrences of discomfort or intimidation during the focus group interviews. Conscious effort was given to preserve confidentiality and trust and identify adolescent perceptions of the PI in an authoritative position, such as in the camp setting where a power differential between adolescents and adults may be perceived. The PIs role as separate from camp staff was clarified during the assent/parental permission process and at the beginning of the focus group interview.

Sensitivity to implementation and management of recording, storage and use of information ascertained in a research study of adolescents with T1DM require scrutiny (Creswell & Poth, 2018). Data collected were stored in a climate-controlled structure to ensure no damage to audio or written data occurred due to environmental conditions in the camp setting. All participants were advised that anonymous data were stored and managed through a text-based computer program maintained on a password-protected computer.

Data Collection

The PI conducted focus group interviews - one with male and one with female adolescents with T1DM - to uncover a deeper understanding of facilitators and barriers to independent T1DM self-management, perceptions of behaviors required for independent T1DM self-management and resources used to engage in independent T1DM self-management. To promote trust and put the adolescents with T1DM at ease, the focus group interviews began with an introduction to the purpose and aims of the research study (Green & Thorogood, 2014). The participants were reminded that any one of them may ask to leave the interview at any time (Green & Thorogood, 2014).

Identification of a private location that ensures confidentiality in a rustic camp setting was challenging (Green & Thorogood, 2014). Conducting a focus group interview in the participants' cabin was considered intrusive (Green & Thorogood, 2014). Therefore, focus group interviews were conducted in a private, vacated, secluded, and air-conditioned kitchen in the healthcare staff's living quarters. Interviews were conducted before camp orientation to minimize disruption of camp activities.

An interview guide (Appendix G) linked to the research questions was developed to guide the focus group questions. An interview protocol that uses open-ended questions provided control of the information desired from the interview but also allowed for both the participants and the researcher to follow new leads uncovered during the interview and data analysis process (Creswell & Poth, 2018; Miles et al., 2014; Bernard, 2011; Riesman, 2002). The PI used open and closed research interview questions. Open-ended questions avoid socially desirable responses by not limiting the respondent's choices but also rely on the participant's experiential inferences and assumptions about what information the evaluator is seeking in response (Schwarz & Oyserman, 2001). Closed-ended questions eliminate this ambiguity but also provide the participants with cues that increase the risk of socially desirable responses, and are therefore preferable to open-ended questions (Schwarz & Oyserman, 2001). The PI encouraged all participants to participate. At times, the focus group was dominated by particular participants, and some participants showed reluctance in answering questions, so the questions were repeated and directed toward other participants to elicit their responses.

During each of the focus groups, audio recordings via digital tape recorder placed in the center of the focus group participants, coupled with handwritten notes and memos assisted in capturing participant behaviors and researcher self-reflections (Creswell & Poth, 2018; Munhall, 2012; Bernard, 2011). The PI used jottings as anchors for follow up questions to clarify questions later in the interview (Bernard, 2011; Rubin & Rubin, 2005) Probes encouraged and stimulated continued conversation from the participants during the interview process (Bernard, 2011; Rubin & Rubin, 2005).

To ascertain the details of the self-management behavior skills required for the adolescent with T1DM during transition from dependent to independent T1DM self-management and the facilitators and barriers of everyday participation in self-management behaviors for adolescents with T1DM, the focus group interview opened first to seek understanding of the steps of diabetes management, “Tell me about what you think the self-management or behavioral skills are that you will need to do when you are taking care of your T1DM by yourself.” A structured approach using closed and open-ended questions and probes elicited further detail and description of the shared facilitators and inhibitors to adolescent T1DM independent self-management (Thorne, 2016; Malterud et al., 2015; Roulston, 2010). For example, the closed-ended question of, “Do you think that you are able to change any of the behaviors of people that make it harder for you to manage your BG levels?” was followed by open-ended questions of “What behaviors do you think that you can’t change?” The dynamics among participants to inform the development of transitional programs facilitated trust between the campers and PI (Thorne, 2016; Malterud et al., 2015; Roulston, 2010). Stronger and clearer communication promoted comprehensiveness and saturation of data (Malterud et al., 2015).

The step-wise process of responding to a question begins with understanding the question and is followed by a recall of relevant behaviors, inference, and estimation of the topic, mapping the answer into a response format and editing the answer to provide a socially desirable response (Schwarz & Oyserman, 2001). Differences in question interpretation may impede this process. Therefore, it was important that the PI defined unfamiliar and ambiguous terminology such as the definition of facilitators, inhibitors and independent self-management and clarified the pragmatic meanings of a question for participants, such as in the question, “Who helps you

manage your blood glucose levels when you're low or high, when you have hypoglycemia and hyperglycemia?"

Formulating a self-report is a cognitive and communicative process of understanding what information is being asked for and retrieving that information from memory. Reference periods were used to influence a question in the same way as frequency based upon the severity of a given situation and its implied meaning (Schwarz & Oyserman, 2001). For example, asking the adolescent, "Over the past couple weeks, what have you, yourself done that made it harder for you to independently self-manage your T1DM?" lead the participants to differentiate routines during the school year versus behaviors over the summer while school is out.

Question context refers to the respondents' perception of the clear and appropriate application of the question in a circumstance (Schwarz & Oyserman, 2001). The PI was aware that her affiliation may influence a response by providing cues to the nature of the assumed response (Schwarz & Oyserman, 2001). For example, there are variations in diabetes management in the camp setting versus home management. As the focus group took place in the camp setting, conducted by the PI who volunteers in the camp setting, the interview question asking about peer facilitators at times elicited responses relating to the relationships they built in the camp setting.

Understanding of both literal and pragmatic meanings of the vocabulary that constructs a question is necessary to construct an appropriate response (Schwarz & Oyserman, 2001). Rigorous interviewing procedures versus allowing the PI to explain or reclassify an interview question to allow for understanding both have risks. Memory decreases over time and memories of frequent behaviors blend into single generalized knowledge representations indistinguishable

from each other (Schwarz & Oyserman, 2001). Reference periods were used as cues of recall. Longer reference periods result in more guessing and estimation, and shorter reference periods might eliminate participants who do not frequently engage in certain behaviors, such as asking the participant's if they had ever been bullied versus recent experiences of bullying (Schwarz, & Oyserman, 2001). Appropriately selected cues, such as what, where, and who improve recall, but resemble close-ended questions which can constrain inferred responses (Schwarz & Oyserman, 2001). The length of the reference point and the specificity of recall cues also impact the number of episodes of a given event reported, resulting in overestimating small numbers of episodes and underestimating many episodes (Schwarz & Oyserman, 2001).

Although breaking questions into parts increases reported frequency, it does not increase accuracy so may result in overestimates of a low frequency of events and underestimates of a high frequency of events (Schwarz & Oyserman, 2001). When given more time to search in memory, recall is more successful (Schwarz & Oyserman, 2001). Closed-ended questions help allow the participant to ponder lists of events. The open-ended question, "Do you all have pediatric endocrinologists and primary care providers?" was further probed by asking, "What do you think are the difference between pediatric and adult healthcare providers?" The process of retrieving memory is improved when searching most recent events first then regress except for retrieving a logical sequencing of events (Schwarz & Oyserman, 2001). Reference periods to memory must be defined, or they can be misunderstood (Schwarz & Oyserman, 2001). Asking what has occurred over the past day could be interpreted as during daylight hours from the prior day, or it could mean over the past 24 hours. By anchoring the question to a specific period, a specific event, memories can be more efficiently retrieved (Schwarz & Oyserman, 2001). The

focus group interviews achieved data saturation after 45 minutes with the male participants and the focus group interview achieved data saturation after 65 minutes with the female participants.

Data Management

All participants were advised that anonymous data would be stored and analyzed through use of audio recordings of the focus group, handwritten field notes, memos, and interview transcriptions of the audio recordings (Creswell & Poth, 2018; Streubert & Carpenter, 2011). These data were uploaded, safely stored and managed in Atlas.ti, a computer-assisted qualitative data analysis software (CAQDAS). All data were maintained on the PI's password-protected computer (Creswell & Poth, 2018; Streubert & Carpenter, 2011).

Data Analysis

Qualitative content analysis- the strategy of choice in a qualitative description study, allowed for coding of data and identification of themes that describe the perception of independent diabetes self-management by adolescents with T1DM (Sandelowski, 2000; Sandelowski, 2010; Loescher et al., 2009; Ferrer, Cianelli, Villegas, Reed, Bernales et al., 2016). Quotations were used as examples to support the definitions of themes as they apply to the facilitators and inhibitors of independent self-management of the adolescent T1DM. Qualitative content analysis resulted in hypothesis generation and support for the development of future studies.

Qualitative description methodology does require some interpretive skill and is, therefore, subject to the influence of the PI (Sandelowski, 2010). Data saturation is dependent upon the depth of information desired by the PI and the continuity of themes that evolve from those interviews (Creswell & Poth, 2018; Malterud et al., 2015; Munhall, 2012). Saturation of data

ultimately means that redundancy of data, themes, and coding is achieved, and the study can be replicated (Munhall, 2012). Clear communication between the PI and participants facilitated data saturation (Malterud et al., 2015) through active listening and sensitivity to the verbal and nonverbal responses of participants assisted with understanding the perceptions of participants (Sandelowski, 2010 The development of precise predetermined and evolving code definitions resulted from the exhaustive and consistent data provided in the study and supported the trustworthiness of data analysis (Miles et al., 2014).

Several concomitant coding methods were used to summarize and categorize interview data. Coding data is a process that assigns symbolic meaning to data, identifies patterns in data, and classifies and organizes data into emergent categories for analysis (Saldana, 2014). The code itself is usually a summative or salient word or short phrase that captures the essence of the collected data (Saldana, 2014). Paragraphs from field notes and interview transcripts were first pre-coded into shorter phrases (Saldana, 2014). Data were clustered and categorized to reorganize and order the data (Saldana, 2014). In vivo and emotional coding using phrases and words spoken by the adolescent with T1DM provided insight to adolescent T1DM understanding of and engagement in independent self-management and the language of T1DM, clarifying the personal views of self-management and transition behaviors (Miles et al., 2014). Evaluation coding methods captured the positive and negative values assigned to the facilitators and inhibitors of independent T1DM self-management by the participants and supplemented in vivo and emotional coding (Miles et al., 2014). Simultaneous coding methods deciphered multiple meanings ascribed to data collected (Miles et al., 2014). The conceptional framework generated deductive categories for initial deductive coding and development of the research questions

(Miles et al., 2014). Development of initial codes using a deductive approach allowed for further revision of codes, and new themes to emerge inductively (Miles et al., 2014).

Potential for Risk

Participation in this study involved no greater risk (minimal risk) than daily life during the focus group interview.

Trustworthiness

Trustworthiness in a qualitative study is established through criteria that include: credibility, transferability, dependability, and confirmability of data collection and analysis (Lincoln & Guba, 1985). Strategies used to ensure the credibility of this study included prolonged engagement with the phenomena of interest, triangulation, and peer-debriefing (Streubert & Carpenter, 2011). Triangulation is a way of analyzing data from multiple perspectives, which in this study included the observations documented in jottings and memos, the demographic information sheets, and audio recordings (Streubert & Carpenter, 2011; Lincoln & Guba, 1985). Corroboration with the PI's advisor who was impartial to the data was used in place of peer debriefing to validate impartiality and establish credibility of data (Lincoln & Guba, 1985). These strategies substantiated themes and patterns through the collected data (Streubert & Carpenter, 2011). Finally, as an additional component of trustworthiness, the use of reflexivity or the PI's awareness of her own biases, values, and experiences that become part of their study, were identified (Creswell & Poth, 2018; Munhall, 2012). The PI recognized her biases as a parent of an adolescent with T1DM, her professional value system as a NP who practices under the guidelines of the American Diabetes Association (ADA), and her experience as a NP at Camp Possibilities summer camp for children with T1DM. In the latter position, the

PI had intimate personal and healthcare knowledge of the participants outside of this study, some from years prior to the study.

Credibility

Credibility is the "truth value" or confidence that the study findings present accurate descriptions of a phenomenon established through prolonged engagement and investment in the phenomenon of interest and their culture (Lincoln & Guba, 1985). Trust is a developmental process that builds confidence, pledges anonymity and involves the subjects in the process of inquiry (Lincoln & Guba, 1985; Munhall, 2012). The camp environment provides physical, psychological, and psychosocial safety, encourages expression and communication, and protects the privacy of adolescents with T1DM. Conducting focus group interviews in the camp environment promoted rapport building with participants, which lead to quicker saturation of data (Thorne, 2016).

Credibility may be established by the PI's presence as an immersed observer of camp activities having prolonged engagement with the research population during the week-long summer camp (Streubert & Carpenter, 2011; Lincoln & Guba, 1985). However, the PI must remain wary of becoming so immersed in a study group that the researcher's presence contributes to the research (Lincoln & Guba, 1985). This is later addressed by reflexivity.

Triangulation was used to cross-reference multiple data sources such as field notes and interviews (Streubert & Carpenter, 2011; Lincoln & Guba, 1985). Continuous planning, self-evaluation, and the use of dairies and journaling assisted in self-analysis that maintained objectivity as well as the credibility of the study (Creswell & Poth, 2018; Munhall, 2012; Jootun,

2008). Peer debriefing with the dissertation chair, Dr. McEwen, who is a qualitative research expert, facilitated the development and testing of further study.

Transferability

Transferability refers to the production of sufficient descriptive real and natural data regarding a phenomenon to transfer that data to other contexts with other participants (Lincoln & Guba, 1985). Transferability does not assume generalizability, but rather the PI's ability to conduct the study in an alternative environment (Lincoln & Guba, 1985). Conventional threats to validity must be accounted for and are considered judgments of transferability of findings to other environments rather than factors that undermine a study (Lincoln & Guba, 1985). The attainment of sufficient descriptive real and natural data regarding the facilitators and inhibitors of independent self-management of adolescents with T1DM during the focus group interviews supports the transferability of findings to other environments.

Dependability

Dependability is the consistency, stability, and predictability of study findings and the ability to replicate the findings with the same or similar subjects in the same or similar context (Lincoln & Guba, 1985). Observable change is the result of instability and factors related to the phenomena or study design (Lincoln & Guba, 1985). Dependability of a study is interdependent with the credibility of a study but must be further discriminated (Lincoln & Guba, 1985).

Confirmability of Data Collection and Analysis

No methodology can perfectly preserve objectivity, but three perspectives of neutrality were considered in this study. The first perspective of neutrality is that objectivity exists with the similarity between the study data and reality, a perspective from which objectivity is untestable

(Lincoln & Guba, 1985). The second perception and naturalist's definition of neutrality removes the emphasis from the PI and places it on the confirmability of the data (Lincoln & Guba, 1985). Objectivity exists when an appropriate methodology is employed that maintains the distance between the observer and the observed (Lincoln & Guba, 1985).

The third perspective of neutrality is that objectivity exists when the inquiry is value-free, and it is possible to allow nature to speak for itself without impact from values of the inquirer or any cohorts (Lincoln & Guba, 1985). The naturalist's analysis of study data would base trustworthiness on the study data and not necessarily on the influence of the researcher (Lincoln & Guba, 1985). Neutrality and objectivity exist through naïve realism- when an appropriate methodology is employed that maintains adequate distance between the observer and the observed so that study conclusions reflect the subjects' perspective (Lincoln & Guba, 1985).

Confirmability requires an accurate reflection of the data rather than the viewpoints or biases of the researcher (Lincoln & Guba, 1985). To address this criterion, the PI provided specific information about how the findings were determined. An audit trail was maintained, in the form of a recording of all study activity so that others may clearly follow the evidence that led to the study conclusion (Streubert & Carpenter, 2011). This audit trail included specific detailed information including transcripts from interviews, field notes, notes from the data analysis process, and procedures (Lincoln & Guba, 1985). Additionally, the dissertation chair, Dr. McEwen, has significant expertise in studying the phenomenon of diabetes self-management, and reviewed each transcript and participated in the data analysis process.

Reflexivity

Truth value is the ability of a study to establish a relationship between reality and the study results (Lincoln & Guba, 1985). Reflexivity is important in clarifying the conditions of recruitment and data collection and specifying possible threats of "truth value" that are influenced by the PI's conscious or unconscious study bias (Jootun, 2008). The process begins with explicating assumptions and biases held by the PI about the phenomenon under study. Familiarity with self- management practices of the adolescent with T1DM and empathy for the barriers to independent self-management assisted in assimilation and trust of the participants, however, the influence of the PI's personal and professional knowledge on data collection and interpretation must be considered (Jootun, 2008).

An assumption of this study was that the participants responded honestly to the research interview questions. Some of the participants had attended Camp Possibilities in the past and were familiar with the camp environment, other campers, and the PI. The camp setting is one of mutual trust and respect between campers and healthcare staff. A second assumption was that this respectful relationship was maintained between the PI and the research participants.

Honesty and trust are reciprocal in a relationship (Jootun, 2008). The PI facilitated honesty and trust among participants through assurances of privacy and confidentiality. Participants were advised that the research outcomes may assist with the development of a transition programs for adolescents with T1DM including the leadership program within the camp setting.

Barriers to data collection and the biases brought to the camp environment must be considered in the qualitative description study of the facilitators and inhibitors of independent

self-management of adolescents with T1DM. The study sample was recruited from a population of voluntary applicants. Applications to the camp are voluntary, and the number of adolescents with T1DM admitted to the leadership program are limited to 10 girls and 10 boys, which limited maximum variation sampling. Further, the unequal proportions of male and female adolescents with T1DM in this study may impact the transferability of the data to another similar setting.

The PI carries both practical knowledge and experience as a nurse practitioner and personal knowledge as a mother of an adolescent with T1DM, and personally understands the critical need for adolescents with T1DM to be transitioning from dependent to independent self-management during this developmental period. In the setting of a summer camp for children with T1DM, this personal and professional insider role carries important individual and professional resources that contribute to knowledge development and decision-making behaviors (Chinn, 2015). The familiarity of the researcher with the study population facilitated understanding of the culture and language of the adolescent with T1DM. A lack of understanding of the internal chaos of an adolescent with T1DM could hinder reciprocal trust (Jootun, 2008). Still, an intuitive response to children with T1DM combined with an understanding of and experience in implementation of safe practice guidelines in practice, can bias interpretations of observable data. The use of continuous planning, self-evaluation, and self-analysis-maintained objectivity and credibility of the study (Creswell & Poth, 2018; Munhall, 2012; Jootun, 2008).

Summary

A qualitative descriptive methodology was used to explore the adolescent's understanding of independent T1DM self-management behavior skills, their perception of the facilitators and inhibitors of everyday participation, and their use of resources when engaged in

independent T1DM self-management behaviors. The qualitative description design provided a comprehensive understanding and summary of T1DM independent self-management within the adolescent environment. Qualitative methodology, the research questions, and the interview guide questions guided identification of self-management behavior skills required for, and the facilitators and inhibitors of everyday participation in independent self-management behaviors for adolescents with T1DM (Sandelowski, 2000).

Conclusion

The study method, sample and setting, recruitment procedures, human subjects protection procedures, data collection, analysis and management plan, the potential for risk, the role of researcher and plan to ensure trustworthiness are described. The study results will contribute to the current knowledge and inform future transitional program research and development for adolescents with T1DM.

CHAPTER 4: RESULTS

Description of Sample

Demographic data was collected on all participants (Table 3) using a demographic information sheet (Appendix C). A total number of 11 participants participated in this study. A total of six Caucasian and one African-American/Latino female adolescents with T1DM participated in the study. They were 15-17 years of age and between sophomore and senior year in high school. The range of years carrying a T1DM diagnoses reported by female participants was 2-15 years. In terms of receiving formal diabetes education, all except one female participant reported participation in discussions of nutrition, physical activity and transition from pediatric to adult healthcare with their parent/guardians or healthcare provider. One participant reported having past discussions regarding nutrition with their parents/guardians or healthcare provider but no discussions regarding physical activity and exercise or transition from pediatric to adult healthcare. All the female participants expected to transition from pediatric to adult healthcare at the age of 18 years old.

Five Caucasian males ranging from 16-17 years of age in their sophomore or junior years of high school participated in the study. The range of years with the diagnosis of T1DM reported by male participants was between 4-12 years. All except one 16-year-old male participant reported discussions of transition planning with their healthcare providers. All the male participants reported discussions regarding nutrition and physical activity and exercise with their parents/guardians or healthcare providers and expected to transition from pediatric to adult healthcare at the age of 18 years old.

TABLE 3. *Participant demographic data*.

	Female (n=7)	**Male (n=5)**
Age		
Mean	16	16
Range	15-17	16-17
Racial or ethnic category identified		
Caucasian	6	5
African-American	1	0
Latino	1	0
Grade Level		
Sophomore	2	
Junior	2	2
Senior	3	3
Years of T1DM diagnosis		
Mean	8.7 years	8.6 years
Range	2- 15.08 years	4.9-12.4 years
Percent who have discussed transition planning with parents/guardians or healthcare provider	57%	60%
Percent who have discussed transition topics with parents/guardians or healthcare provider		
Nutrition	100%	100%
Physical activity and exercise	85%	100%
Future career or vocational counseling	85%	80%
Age planning on transfer from pediatric to adult healthcare	18 years old	18 years old

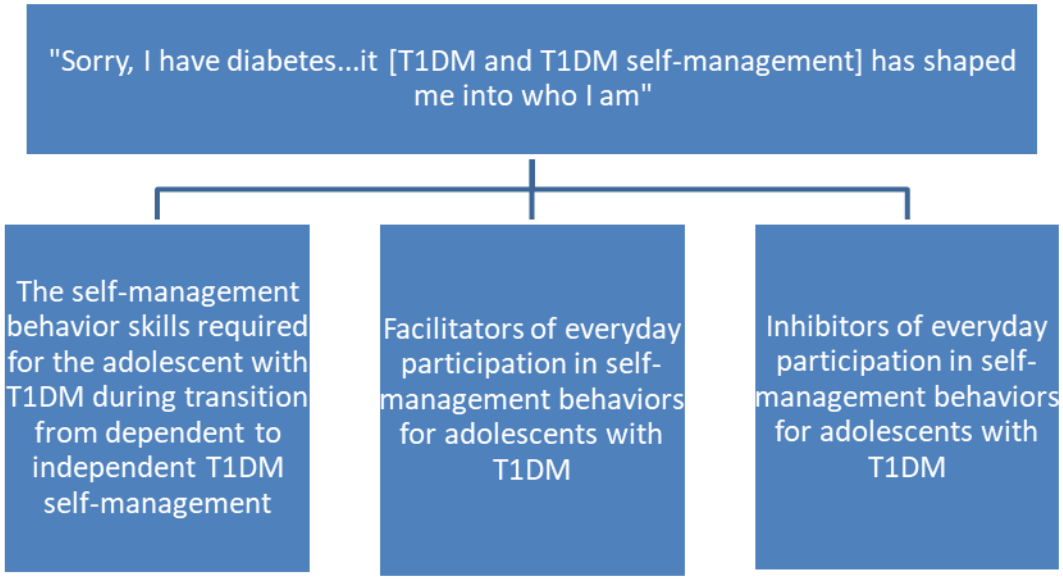
Findings

Through an iterative process, the data from semi-structured interviews were analyzed and the data were best represented by an overarching theme, “Sorry, I have diabetes….it [T1DM and T1DM self-management] has shaped me into who I am.” Most female and male participants expressed an acceptance of T1DM and its management as part of who they were or “something you just sort of do.” Female participants expressed indifference to the painful aspects of disease management, such as needle sticks, agreeing with one female participant who stated, “Even if somebody … stabbed me, I'd be like, ‘It’s cool.’” One female participant added, “Some days, I honestly, I don't mind it [having T1DM]. Some days, I wouldn't trade it for the world because it [T1DM and T1DM self-management] shaped me into who I am.” However, for most of the

participants, this was not a consistent or persistent sentiment, with the female participant continuing her statement, “But other days, I'm like please take it [T1DM and T1DM self-management] away from me. I don't want anything to do with it.” This latter sentiment is what wears on the daily existence of adolescents with T1DM.

Three domains that supported the overarching theme emerged from the conceptual framework of the study (Table 4). These domains were *Self-management behavior skills required for the adolescent with T1DM during transition from dependent to independent T1DM self-management; Facilitators of everyday participation in self-management behaviors for adolescents with T1DM*; and *Inhibitors of everyday participation in self-management behaviors for adolescents with T1DM*.

TABLE 4. *Overarching theme of study*.

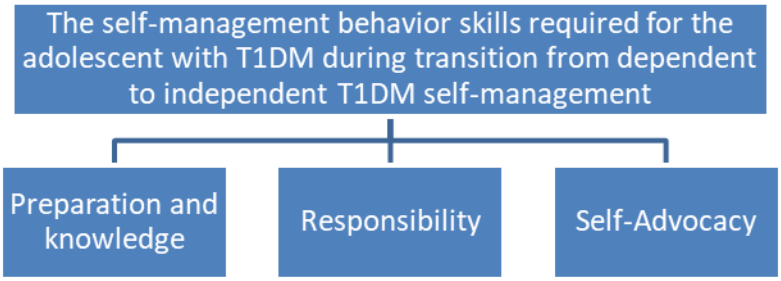


Self-Management Behavior Skills Required for the Adolescent with T1DM During Transition from Dependent to Independent T1DM Self-Management

Three subcategories emerged which described the participants' perceptions of the self-management behavior skills required for transition from dependent to independent T1DM. The subcategories included *Preparation and Knowledge, Responsibility*, and *Self-advocacy*. Preparation and knowledge highlighted the participants' understanding of the effects of T1DM on their bodies and the behaviors required to promote health and prevent unwanted health outcomes.

TABLE 5. *Domain 1*.

Facilitators of everyday participation in self-management behaviors for adolescents with T1DM



Preparation and knowledge. Preparation and knowledge addressed the participants' understanding of etiology and management of T1DM. Knowledge required for independent T1DM was explained by one adolescent male as, "Just knowing your own body is the most important part… after that, correcting it is easy…. It's just knowing when to do it [correct for low or high blood sugar] and [responding to] how you feel at that certain time." "and what-- and how you feel at that certain time." Another male participant added, "You definitely need to know how different things you do affect your blood sugar, know what makes you go low or high, and kind of specifically how that affects and kind of be able to tailor it with ease."

One male participant stated, "….one of the most important things for me is knowing what type of food you're eating … different types of food will stay in your system for longer or shorter [time] and when you give yourself insulin based off of whatever food … have to take it into consideration how quickly you're going to drop [blood sugar] from … food." Proper preparation was also dependent upon the adolescent's willingness to adapt and change based on their disease process. "… my basal might be one unit during the day, but at night it has to go up… so, just noticing those sorts of trends and being able and willing to sort of adapt to those really makes a difference."

One female participant stated that she was informed, "… that doctors don't want type 1 diabetics exercising and such… I don't agree with that… Because it helps me manage my blood sugar." Personal knowledge of the effects of physical activity on her body enabled her to challenge and eventually disregard the misinformation she received. One male adolescent correlated maturity with increased knowledge and understanding their personal self-management needs stating, "Just as you mature and get older and understand more the kind of impact that it [T1DM] has [on his body]."

Female participants also identified the importance of self-managing co-morbid conditions such as depression, Celiac disease and sleep apnea in addition to their T1DM self-management needs. For instance, one female participant stated, "I have different sleep issues… severe sleep apnea… that means I'm not getting the quality rest, so I want to sleep later." Another participant addressed the need for early identification of depression, "We need to take care of our mental health, … if someone's depressed they're just going to lay in bed… not going to be motivated to give themselves insulin … once you fall into that, … makes it spiral and … [I] think…'Am I ok?

Can I do this on my own?'" Participants with co-morbid conditions must have adequate preparation and knowledge of both T1DM and their co-morbid conditions' etiology and management.

Responsibility. Responsibility was defined as the willingness of the participants to take on the behaviors of independent self-management, Responsibility included changing insulin pump sites, taking medications, setting alarm clocks to remember to take insulin, preparing a backpack with needed supplies and maintaining a routine. Female participants explained that "Changing your pump [site] on time … actually do it every two days [is being responsible]." A female adolescent explained responsible behaviors of independent self-management as, "… don't just eat your snack in bed, … get up go get your insulin, your needle … and actually take the insulin …" Female participants agreed that maintaining a schedule in the summer similar to that of their school years assisted them in adhering to responsible behaviors of independent self-management.

Examples of being responsible were addressed by four different male participates. "I normally keep a sleeve of glucose tablets near the door so … it's easy to get." "I also have a little red bag with my testing kit … glucagon and other little snacks…" "If you're not going to be anywhere where you could buy sugar or carbohydrates, you definitely need to make sure you bring your own otherwise you could be just out of luck." "On longer trips, you definitely need to prepare in advance … always thinking, 'What do I need? What is the worst that can happen?' and preparing for that."

Self-advocacy. Participants developed safety nets within their communities and to do this they needed to be able to communicate their needs and educate members of their communities

through self-advocacy. Participants self-advocated within their social network by teachingT1DM self-management and early identification and prevention of symptoms of hyper- or hypoglycemia. Their social networks included teachers, coaches, and peers. Two male participants stated, “I think it’s important to speak up for yourself and communicate when you’re [blood glucose levels are] low or high or you’re struggling to manage your diabetes, because it’s important to know when you’re going to be on your own you’re not going to have people there to support you or tell you what to do. So, you’re going to have to be responsible and be an advocate for your own health.” Another male participant stated, “I brought my teachers this little snack kit and sort of explained [about management of hypoglycemia] … ‘Keep it in your desk.’ … so that I would notify them [of symptoms of hypoglycemia], and they could keep stuff on hand in case I [his blood glucose] was dangerously low and couldn’t make it to the nurse.”

Male participants who were also athletes highlighted the importance of educating their coaches about T1DM etiology and management. A male participant shared a call his family received from his coach following his diagnosis of T1DM. “I got a call from an old baseball coach … he found out over the phone [that the participant developed T1DM] and he gave my parents a call [concerned about his involvement in the diagnosis] ‘I didn’t see him eating candy or whatever or doing-- I didn’t see him eating whatever sugar.’ And, so, we had to politely explain that eating sugar was not why I developed diabetes conditions.”

Participants would self-advocate by targeting specific individuals to educate about their signs and symptoms of hypo- and hyperglycemia. A male participant stated, “Whenever I hang out with a group of friends that aren’t really too knowledgeable about diabetes and the way blood sugar can affect you… I basically tell them how I act… when my sugar either goes too low or

too high, so that they can get my attention, let me know that I'm acting slightly out of the normal, and get me to test my sugar." Another male participant explained, "I play a couple sports and, so, knowing that my coaches know [about T1DM self-management] is probably the most important thing …I don't need to teach 10 friends how to do this [administer glucose, identify signs/symptoms of low blood sugar] when I can just teach the coach who will always be there."

Participants agreed that as children, their parents would educate community members on their disease and disease management, but during adolescence, it became their responsibility to self-advocate. Most of the participants did not express difficulty in self-advocating with peers. One boy stated "Whenever I hang out with a group of friends that aren't really too knowledgeable about diabetes and the way blood sugar can affect you and make you pass out or things like that, I basically tell them how I act or how I know that I personally act when my sugar either goes too low or too high, so that they can get my attention, let me know that I'm acting slightly out of the normal, and get me to test my sugar."

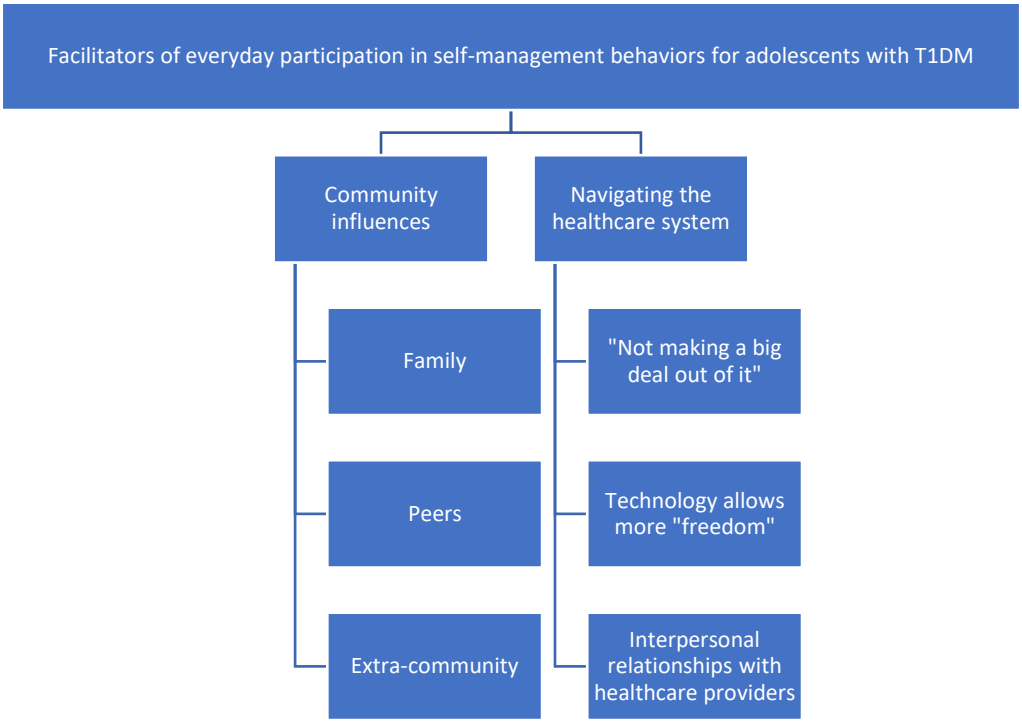
The male participants talked about going to college after graduation from high school. One male participant contemplated the impact of choosing a meal plan and developing relationships with food service personnel while away from home, "… if you need to eat at certain times, maybe an unlimited meal plan versus a traditional meal plan might be better for you… being able to customize your meal plan to fit your needs."

Facilitators of Everyday Participation in Self-Management Behaviors for Adolescents with T1DM

Two subcategories emerged which described the *Facilitators of everyday participation in self-management behaviors for adolescents with T1DM*. These subcategories included

Community influences and Navigating the healthcare system. Navigating the healthcare system described the participants' interpersonal relationships with their healthcare providers, and the participants' perceived abilities to attain the necessary diabetes supplies, medications, and healthcare insurance to independently self-manage T1DM.

TABLE 6. *Domain 2*.



Community influences. Community influences branched into subcategories of the participants' *Families*, *Peers*, and *Extra-Community*.

Family. Overall, with parental encouragement and trust, participants felt empowered to independently self-manage their T1DM. "Because sometimes she's so supportive and she's, like, "Well, you do what you feel. It's your body and you know what you feel like." All participants felt like they could safely and independently self-manage their T1DM "I could do it [self-manage blood glucose excursions]. Maybe not the most flawlessly, but I could definitely do it…," but

having a parent to assist them when they are in trouble is helpful, to “kind of bounce ideas off each other, feedback, kind of see what the best treatment would be…. you know, just try to get me back on track.” And for overnight glucose monitoring “Sometimes it’ll drop a little low and I sleep right through the alert, the alarm. So, they’ll wake up and they’ll help me.”

Feeling respected and trusted by their parents in their abilities to perform independent self-management was important. “So, for us, our parents are kind of just, ‘They're older now. They've had it for a while…. but they’re, like, we’re okay.’" Many participants were comforted by the safety net of a parent resource. “During the day, I’m pretty on my own with that; not because they won’t help, but just because I can do it myself unless I’ve done something horribly wrong with some sort of calculation or something.”

The participants identified the benefits of the insulin pump and continuous glucometer (CGM) with alarms as helpful tools for their parents to assist them in monitoring their glucose levels during the night. One participant also considered the need for resources for their support networks to improve their skills in supporting the adolescent’s independent self-management. She suggested programs to support their family members may be beneficial “And I feel like not only should we develop stuff for camps, but I think there needs to be something [support networks] that… that are more accessible too… parents…relatives.”

Peers. As participants discussed interpersonal relationships with their peers, two different peer groups emerged from the data: One with T1DM and another without T1DM. Most of the participants had positive support networks comprised of peers without T1DM. One female participant stated, “A lot of my friends have tried to learn it [T1DM management] because they know it's such a big part of my life.” The amount of support provided by peers without T1DM

depended upon the motivation of peers to help, and the desire of the adolescents with T1DM to engage peers in their independent self-management.

Female participants credited the level of "awareness" of T1DM and its management their peer possesses to the impact of their peers without T1DM to facilitate independent self-management. "So I know if I fall over in the middle of a restaurant… they'll [the participant's peers] have an idea of what to do… they might not know if I'm [her blood glucose is] low or high, but they know where my pump is on me. They know how to check it [her blood glucose level] on my phone." The level of understanding of the urgent and emergent signs and symptoms intimate to the adolescent with T1DM was important as well. "And they [the participant's two best friends without T1DM] both said that whenever my blood sugar goes high, I literally just look like I'm drunk… So, it's very noticeable."

The degree in which their friends engage in the learning about T1DM was important in helping one female participant independently self-manage T1DM "Just having friends that are willing to learn it [T1DM management] helps." One male participant stated that "as long as they [his friends] know just the most basic, simple diabetes stuff" was important in keeping "a watchful eye and just help you out… just knowing that if you've been running around for a while, 'maybe you need to eat something?'"

All of the male participants planned on going to college after graduating high school. One male participant was very hopeful that his social transition to college would be smooth. "I figured it would be interesting to see if you get a roommate, how the roommate handles diabetes. And I don't think-- it might not be any different than any of your friends."

Most participants agreed that bullying behavior over their diagnosis of T1DM stopped after childhood. Participants reminisced on several times during childhood in which they were ridiculed for having T1DM. Female participants agreed with one female participant who placed the blame on the parents of the bullies, stating if "…adults are ignorant… that…creates more ignorant generations. And that's an issue with it [bullying over having T1DM], too." One female participant stated, "I feel like it's [bullying behavior occurs] more when you're younger when children are… naïve and stuff versus when you're older… your friends that know [you have T1DM] …Nobody cares." Male participants agreed, "Usually, people hear diabetes and they think, 'big medical emergency'. So, they don't really like to touch that topic a lot, so they don't really make fun of it all too much."

Adolescents with T1DM that share both the commonality of carrying the T1DM diagnosis and have an established bond of friendship have additional benefits of understanding and assist with trouble shooting in independent self-management. One female participant stated that "just helps to have that network [of peers with T1DM]". Another female participant agreed, "… generally, to have other people that you know with diabetes… [to ask] 'Hey, what do you do if this happens? Hey, how do you do this?' And they… know [how to self-manage T1DM]." One female participant stated she was invited to attend a [T1DM] "diabetic therapy group" but refused stating, "It needs to be with friends… people that I can get along with, not just any diabetics." Participants perceived that support from other adolescents with T1DM still required a bond of friendship to be effective.

This social networking amongst peers with T1DM was demonstrated at the end of the female focus group interview. Female participants began a discussion about functions of their

insulin pumps and offered assistance to another who requested guidance in troubleshooting insulin pump settings. The female participants also made plans to continue their discussions regarding independent self-management in their cabin following the focus group interview. One female participant stating that she felt "20 pounds lighter" after getting the opportunity to discuss their feelings and opinions on T1DM management with their peers with T1DM and another offered creating "a camp diabetic counseling group." These behaviors demonstrated the importance of support from peers with T1DM as facilitators of independent self-management.

Extra-community. Many participants stated that during childhood their parents would go to their schools to educate staff and students on T1DM, but as they got older, they held the responsibility to educate teachers on ways that the school could help them to independently self-management T1DM. Two female participants described attending high school "Biomed" and "Allied Health" classes that included a diabetes education curriculum. The female participants were given the opportunity to not only teach their classmates about T1DM but also clarify areas in which the teachers were ignorant. Both female participants agreed that the classes made a positive impact on their peers understanding of T1DM, "A lot of people in the class didn't understand it [T1DM etiology and management]. So, I kind of had to tell a lot of people in the class what it kind of was. Because they were thinking more type 2…" The other female participant enjoyed her peers' interest in learning about T1DM. "And then the questions [about T1DM] just started piling up and they wanted to learn more [about T1DM], and it was really fun."

One male participant highlighted the benefit of receiving additional accommodations through individualized, disease-specific academic plans on how a school system will remove

barriers of academic success for students with disabilities, known as “504 plans.” “And I know I also have the 504 plan with my testing. So, when I do standardize testing and stuff, the proctor is really good about asking me if I need breaks or if I’m okay with my diabetes. So, that’s always nice.”

The male participants viewed school nurses as positive resources in case of an emergent or urgent situation. “The school nurse knows and, so, obviously, if it gets to the point where you need glucagon or you need something badly, it’ll be noticeable, and they will call in the nurse.” Two female participants agreed that their school nurses tell them to “Come down if you need us,” however most of the female participants did not convey a positive relationship with their school nurses.

For one male participant, development of a safety net extended beyond his community. He identified ways that society could facilitate independent self-management. “It would be cool to see with restaurants or whatever, if they had some sort of just fast-acting thing available that you could ask for. That’d be awesome. I don’t know how easy that’d be to implement. Just asking restaurants to have a juice box here or there. Because if you’re walking in and you’re feeling low, you don’t want to wait for a waiter to come over and say-- and order. You need something quick. So, if you don’t have something with you, if they had something available, that would certainly be helpful.”

One female participant noted that society was becoming more accepting of mental health issues. “Because I know mental health issues are becoming more with the mainstream, widespread and acknowledged…having diabetes for nine-plus years it's [depression is] going to

happen every once in a while." All the female participants agreed that T1DM can "trigger" depression.

Navigating the healthcare system. *Navigating the healthcare system* included the use of and access to healthcare insurance, insulin, diabetes supplies. Three subcategories to describe how participants navigating the healthcare system evolved from the data. Participants discussed learning and performing the skills required to access the healthcare system and "not making a big deal out of it", and the importance of *Technology* in independent self-management, and the importance of the *Interpersonal relationships* between participants and their healthcare providers.

Not making a big deal out of it. Participants approached acquiring the skills of independent self-management with nonchalance. One female participant highlighted the importance of learning the skills of ordering insulin pump supplies and equated it to learning telephone communication skills. The participant compared ordering supplies to ordering a pizza and once she acquired that skill, it was no more difficult to order supplies. Male participants viewed obtaining their own health insurance policy upon leaving the family home as a simple process. One male participant stated, "most of the supplies just come from the insurance company… So, once I turn 18, I plan on just continuing to set up a relationship with the same [insurance] company, just sort of move it from my parents' account to mine… I'm going to try to keep it with the same[insurance] company to make it as smooth as possible, to just move on and not really make too big of a deal out of it."

Technology allows more "freedom." Access to technology, such as continuous glucometers and insulin pumps facilitated independent self-management. Female participants

regarded the “CGM”- continuous glucometer as an important facilitator of independent self-management while driving. “You should check before you get in [the car] and you need to have CGMs will help… Because I don’t always feel my lows, but my Dexcom [CGM] will alert me and I know… I need to pull over somewhere.” Another female participant highlighted the benefit of the CGM to prevent a low blood glucose while driving by alerting the participant of a blood glucose that is dropping, “Or you can just take a couple glucose tabs [tablets] and continue driving.” One male participant stated, “I can be a lot lazier with what I do [blood glucose monitoring], knowing that I have my blood sugar tested every five minutes [by the CGM]. So, it allows me to have a lot more freedom with what I want to do, because I can always see my blood sugar and always see if I’m [his blood glucose level is] rising or if I’m dropping.”

Interpersonal relationship with healthcare providers. Participants highlighted communication, trust, and respect between themselves and their healthcare providers as facilitators of independent self-management. Most participants agreed that they learn the fundamental skills of independent self-management skills from their healthcare providers, particularly their endocrinologists. One male participant explained that the bulk of his knowledge formation began with diabetes education and nutritionist counseling, then the family and the participant were expected to practice behaviors of independent self-management between visits. “When you first get diagnosed, they’ll generally send somebody in, like a nutritionist. But, after that, I feel like you and your family sort of take over and you try to take control.”

Another male participant stated that learning the tasks of independent self-management from his healthcare provider increased over time and coincided with his maturity levels “you sort of grow with it.” “When you go in, you’re sort of getting all the information together and looking

at it all at one time. That, you can't really do as much at home. That sort of thing is really helpful, because when they put everything out in front of you and say, 'All right, so, this is what it looks like now. Here's what can make it better.' Then when you go home and you're looking at it the next month or however long it takes you to go back to the endo, then you can implement what they talked about."

The male participants concurred with one male participant who stated his provider's knowledge and skill were important facilitators of independent self-management, "Oh, he's very knowledgeable, yeah. It definitely helps." One female participant stated, "So, she's always been up to date with everything. She always knows the latest information." Participants stated that their pediatric healthcare providers help them in changing insulin settings based on health changes, teaching "glycemic index," "noticing trends," and "keeping it [their BG] steady."

Those participants that expressed positive relationships with their providers reported that their providers communicated more directly with them versus their parents. One female participant stated, "… mine has always listened to me. And if my mom felt like I missed something [a part of T1DM management] or I forgot about a day where I [her blood glucose] was crazy high, she'll mention it and she'll talk about it. She's listening but not interrupting. She knows that I know myself more than anything. She's just there if I forget something or to make sure she knows what's going on."

Participants also favored providers that displayed confidence in the adolescent's ability to troubleshoot T1DM self-management. One female participant stated that her provider encouraged her to troubleshoot some of her insulin pump settings based on consistent trends in her blood glucose levels, "Yeah, well, mine told me that if I'm noticing a trend in my sugars or

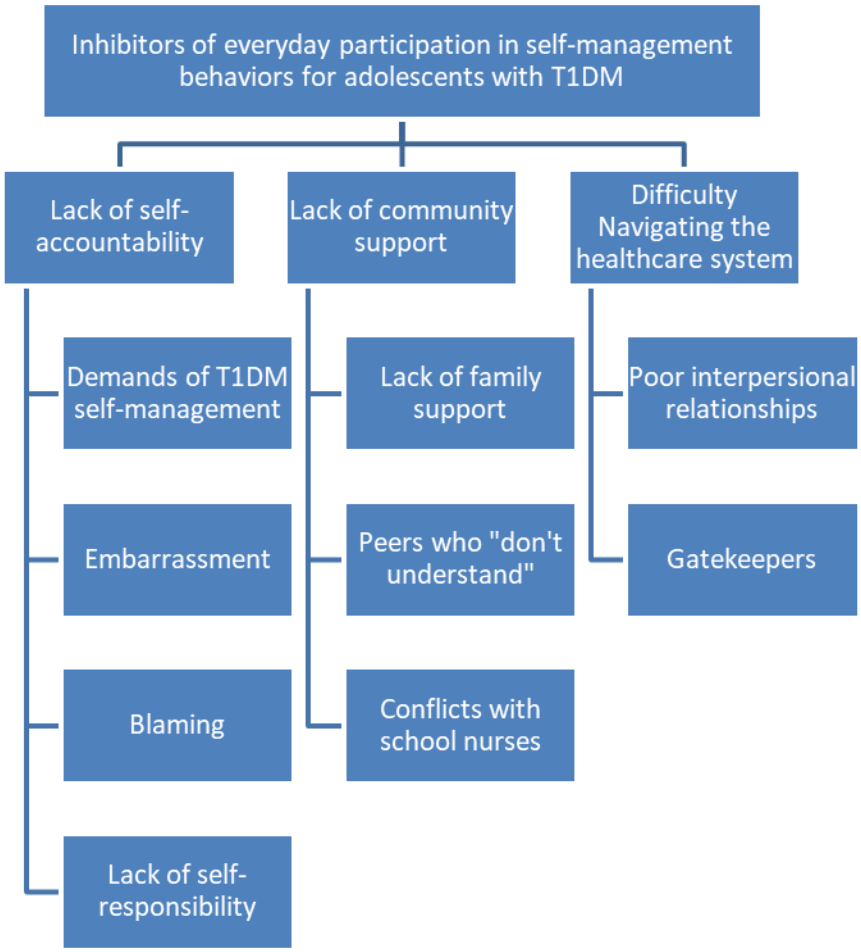
whatever that I can change, like a basal [insulin rate] or something on my pump, and see what happens. She told me to test things out and try it if I want to." Another female participant added, "And I did that once with my carb insulin [ratio of insulin to carbohydrate intake] … at dinner. It was 1:8 but I was always high for dinner, so I changed it and now it's better. So, she does let me do that."

One male participant stated that his healthcare provider "makes me feel like I'm managing some part." A provider behavior that one male participant regarded as favorable was her "focus on the positives" and reassurance "that I'm doing something well and that she's boosting my self-esteem before she addresses the things that can be improved upon. So, that way, she keeps my attention and makes me feel like I'm managing some part."

Inhibitors of Everyday Participation in Self-Management Behaviors for Adolescents with T1DM

Three subcategories emerged which related to the participants' *Inhibitors of independent self-management of T1DM*. The subcategories include *Lack of self-accountability, Lack of community support,* and *Difficulties navigating the healthcare system*.

TABLE 7. *Domain 3.*



Lack of self-accountability. Four subcategories described how lack of self-accountability served as an inhibitor of independent self-management. The subcategories included: The participants' frustration with the *Demands of T1DM self-management*, *Embarrassment* over the requirements of disease self-management, *Blaming* the disease process for negative behaviors, and *Lack of self-responsibility*.

Demands of T1DM management. T1DM was predominantly viewed as a demanding, stressful, frustrating and annoying vice. One male participant summed his frustration up stating, "I mean, even though it's a part of me, it's agitating. It's something you got to learn to live with,

but even while you learn to live with it, it's something that, if you think about it, if you compare yourself a lot to another person, or someone else who doesn't have diabetes, it kind of-- it can agitate you and frustrate you."

The female participants very clearly stated that they did not like diabetes, diabetes was hard, and it was unfair, "Type 1 happens to people for no reason, really if you think about it." They sometimes felt out of control of their emotions, mood swings, and hatred of T1DM. "Every once in a while, I'll just have a complete breakdown where I can't do anything, I'm done. And I just cry and then I'm fine." All female participants agreed when one made the statement, "You just need a week off of diabetes," referring to the overall distress of the disease and disease management responsibilities.

The disease process and management can be frustrating for the adolescent with T1DM. "It's not just us. We're not alone in that it's not just our blood sugars that are screwed up because we don't care." Participants expressed frustration with being forced to prioritize T1DM management, "It just lingers in the back of my mind sometimes. When we go on vacation and we'll go out to eat ice cream and they'll just order this big ol' Sundae, you know, without care. And I'm like, "Okay, how many carbs is this?" I got to bolus 15 minutes before we eat, before we even get there." Participant's felt that the burden of T1DM self-management was simply unfair.

Embarrassment. If the adolescent is not comfortable with publicly performing the processes of disease management, this will interfere with self-management. "If you're not comfortable with doing something in public, like taking out your insulin pump and bolus'ing, then you're going to be less likely to take care of it." This may be due to embarrassment over the

disease management requirements, “You don't want to pull out insulin or you don't want to pull out your pump. Or if you're out at certain places around people you don't even know, you don't want to just, if you're in a dress, you don't want to raise your dress and grab your pump or raise it and take a shot.” Or the adolescent’s perspective of how they are viewed by society “Your friends aren't doing it, so you just think, like, you forget sometimes.” T1DM management limited the participants’ privacy and they sometimes wanted to just fit in.

Blaming. Some female participants searched for causes outside of their own self-management behaviors for poor glycemic control. Blame was described by the response of one female participant who stated, “Why would I do this to myself.... [Poor glycemic control] can be something else and, I don't know.” Not understanding the disease process led to blame of poor glycemic control on an unknown event but were also explained later by other causes.

One female participant addressed not being able to feel a change in her body with elevated blood glucose levels. “Because like since I didn't feel it [hyperglycemia]…. at the moment… I don't feel like that bad then because I'm like that all the time.” This adolescent described hypoglycemic unawareness as her body had grown accustomed to being in a hyperglycemic state.

Female participants blamed not only T1DM on poor health outcomes and behaviors, but also carrying co-morbid conditions. For instance, one female participant stated, “And it's not always a diagnosed depression. Sometimes you just fall into a pit where [for] two weeks you just don't feel your best… you lose self-confidence in something or just something's not going right.” “The stress screws your blood sugar up but then your blood sugar is, like, screwing how you feel.

So, it's like they just make it worse." The participant perceived depression and diabetes distress as inhibitors of independent self-management,

Lack of self-responsibility. Participants were required to obtain approval of their endocrinologists to operate a motor vehicle. Approval was based on the adolescent's glycemic control and willingness to adhere to safety rules such as monitoring blood glucose levels before and during driving, and having continued access to insulin, glucose and other supplies while driving. Some female participants admitted to withholding the diagnoses of T1DM with the department of motor vehicles when obtaining their drivers licenses. One female participant stated that they were advised by "the MVA people" that "It's useless [to report carrying the diagnosis of T1DM]. It's just going to say [T1DM] on your license. It makes it harder to get your license because you have more tests you have to have."

There are safety risks to both the adolescent with T1DM and other drivers on the road if the adolescent is impaired due to hypo- or hyperglycemia. One female participant stated, "And if they [the police] pull you over, they have the right to check your blood sugars and things. And if you're [your blood glucose is] too high or too low, they can give you a DUI [driving under the influence] for insulin." "However, the adolescent highlighted the unfairness of this scrutiny, stating "Even if it's [their blood glucose level is] in our personal range of okay, like some of us, we can function at 250. But they consider that too high we get in trouble and I'm fine. I'm not reckless." For some female participants, their definition of appropriate glycemic control was contrary to those placed on them for safe driving.

Many of the adolescent girls agreed that during the summer months they failed to maintain the same schedule they had during the school year. This change of schedule impacted

their sleep schedule, their eating habits, and the frequency of which they monitored their blood glucose levels. One female participant reflected on her time since school ended, “I have an unhealthy sleep schedule. I'm eating at all hours of the day. It's a lot harder in the summer.” Another female participant added, “Me, too, yeah. All I do is sleep. That's all I do.” Altered sleep schedules made the behaviors of independent self-management of T1DM more difficult to maintain.

Prioritizing other activities over glycemic control inhibited independent self-management of T1DM. Participation in sports interfered with the independent self-management of one male participant. “But it’s hard, because when I’m playing soccer or lacrosse or something, my number will rise instead of drop. And there’s not really much I can do, because I can’t wear my insulin pump while playing soccer.” This participant struggled with possible ways that he could participate in sports and maintain glycemic control, but in the end, he decided that athletic participation could not be interrupted by the behaviors of independent self-management.

Adolescent girls pointed out the significant difficulties of co-morbid conditions and how those disease processes interfered with their ability to independently self-manage T1DM. Specifically, a co-morbid condition of depression interfered with their motivation to independently self-manage T1DM. “I have depression now. I was on medication for that, but it's hard, though, but you still got to manage it.” And having a co-morbid condition of sleep apnea led to an inability to maintain the routines needed to independently self-manage T1DM “I have severe sleep apnea-- So then, that means I'm not getting the quality rest, so I want to sleep later [in the morning].” Sleeping later meant that she was not monitoring her blood glucose at regular intervals, eating at regular intervals, nor dosing her insulin properly.

Some of the female participants admitted to using T1DM as a scape-goat. One female participant stated, “It'll [a negative event will] have nothing to do with it [T1DM] and I'll be like, ‘Sorry, I have diabetes.’ And then mainly they're like, ‘Okay, it's fine’.” Another participant laughed stating, “It's kind of like instinct where I just blame it and then they're like, ‘Okay.’" Carrying the diagnosis of diabetes gave them “an excuse” to absolve poor behaviors. “I have the right. I'm diabetic.” This sentiment also contributed to the title of the overarching theme of this study.

Lack of community support. Ignorance and resistance of family, peers and school nurses to assist the participants in independent self-management emerged to describe inhibitors of independent self-management. More specifically, the data identified three subcategories which included: *Lack of family support, Peers who “don’t understand,” and Conflict with school nurses*.

Lack of family support. The participants’ perceptions of parents as inhibitors of independent self-management was dependent on many factors. Inhibitory factors of independent self-management included overbearing or accusatory parental behaviors, the length of carrying a T1DM diagnosis, the adolescent’s fear of parental anger, parental fear of the diagnosis of T1DM, parental distrust in the adolescent with T1DM, parents punishing the participant for lack of independent self-management behaviors, and involvement of the parents in the adolescent’s general and T1DM-specific support networks.

Many female participants agreed that independent self-management was inhibited by negative behaviors displayed by their parents. One female participant stated that independent self-management of T1DM was “so hard if your parents are on top of you… that you can't take

care of yourself. But then it [parental pressure] just makes you feel worse about yourself. You just don't want to [self-manage T1DM].” They accused parents of being “down your throat all the time” with one female stating that her parents “throw it [poor self-management behaviors] in your face.”

One female participant stated, “Some things that your parents say actually hurt,” which results in decreased self-esteem, decreased self-confidence and giving up, “then I just don't want to do it [T1DM self-management] at all.” One female participant responded dismissively to another participant admitting receiving assistance from her mother with self-management of T1DM. “Yeah, but that's [parental assistance is] normal because you were recently diagnosed.” The participant believed that over time, with longer length of carrying the T1DM diagnosis, parental involvement waned.

One female participant explained how fear of parental anger influenced her independent self-management. “So when I do take care of myself [perform T1DM self-management] better, it's more… so they're not mad at me, so that they're not, on my butt about it.” The participant’s motivation for independent self-management was, “not so I'm healthy.”

Parents’ fears of the disease process and poor health outcomes of T1DM was perceived by one female participant as an inhibitor of independent self-management, “My mom was just so scared [of T1DM]. She did not let me [self-manage her T1DM] until I was [pause] yeah, my Mom's still tearing up.” One female participant stated that her father’s fear of her poor diabetes control inhibited her ability to leave her family’s home to attend college. “My dad told me or apparently he told my mom that he doesn't know if he's letting me go anywhere for college because of that [poor independent self-management skills].” She continued to add, “He's not

even a part of managing me at all. It's solely me and sometimes my mom. He literally has no part in it but thinks I don't know what I'm doing." Rather than feeling challenged to improve independent self-management skills, this female participant became resigned stating, "So, I guess I'll live with my dad forever. That's fine."

Other female participants shared frustration with family members who lack understanding of T1DM and their self-management needs, yet still try to influence their self-management behaviors, "Honestly, my family… the people that think they know what they're talking about [T1DM management]but don't, they just ask all these questions [about what she is doing to self-manage T1DM]… They think they know… what I'm supposed to do [to self-manage T1DM] but they're wrong. And then they get on me about it and… I just can't [deal with them]."

Female participants felt like their parents were quick to rescind control of independent self-management. One female participant viewed her mother as "two-sided." stating "…she'll be, like, 'Well, I'm your mother. I know what you are. Your [blood glucose level is] always high or you're always low. You're not doing something right and that's your fault, so let me take control of this [management of T1DM].' And if I messed up once, she'd take everything [her independence in managing T1DM] away." Female participants also perceived parents unfairly rescinded independent self-management responsibilities as a disciplinary action for poor glycemic control.

This sentiment was supported by another female participant who shared how lack of parental trust inhibited independent self-management. She stated that her parents would punish her by rescinding her independence, stating " 'I'm not trusting you for this long [time]. You're

not doing this [self-managing her T1DM] without me watching you. I have to give you your shots. I can't trust you for anything.' The participant further stated that the punishment would also occur during times that they were trying to get back into a "rhythm" of independent self-management, in which they were trying to regain control of their blood glucose levels, but were stopped abruptly by their parents.

Some female participants perceived their mothers as interfering with their ability to self-advocate and build and maintain support networks, particularly relationships with their healthcare providers and school nurses. One female adolescent stated that her mother encouraged her to perform self-management behaviors that contradicted what the school nurse advised, "But then if someone else, like a school nurse is trying to tell you what to do [follow the protocols of self-management as written by the participant's healthcare providers], then they're [her mother is] like, 'You can't tell her [the school nurse].'" This makes problem solving and decision making more difficult for the participant.

Some participants highlighted the lack of psychosocial support from family as an inhibitor of successful independent self-management of T1DM. Number of working parents in the home, demands of other siblings in the family, and not being "blessed" with financial resources were identified as inhibitors of independent self-management. One female participant stated, "It [family involvement is] … different from everybody's home lives… if you have two parents and you're an only child, they're definitely going to help you a lot more. Whereas it's just me and my dad and my sister… she's eight with Down's syndrome, so a lot of attention goes to her… I've learned how to do everything on my own." This participant felt like her father was unable to serve as a resource to her because his attention was on her sister who had special

needs. The lack of parental resource resulted in poor glycemic control and inhibited independent self-management.

Peers with T1DM who "don't understand." The female participants highlighted the differences between adolescents with T1DM who "haven't reached all the stages in your life that they have, so then they look down on you." Female participants expressed the need for support from peers with T1DM who have similar developmental and maturity levels. Participants resented being thrust into adult led "diabetes support group" composed of other adolescents with T1DM with whom they were not comfortable or friends.

Peers without T1DM who "don't understand." One female participant described the meaning and burden of "peer pressure" from other adolescents without T1DM. "Peer pressure for different things. Not drinking and drugs. But I'm talking about your friends that are like, 'Oh, come out.' And you're like, 'Mmm, I can't. My blood sugar's high and I don't feel good.' And they're like, 'Just come anyway.'" Other female participants agreed and one highlighted similar pressure from coworkers and employers "jobs where you're like, 'I need to sit down and take a break'... and they're, like, 'No.'" Peer pressure as described by some of these female participants inhibited independent self-management and also delayed treatments that could have immediate detrimental health outcomes.

According to one female participant, peers without T1DM would disregard T1DM self-management due to not understanding the significance of their symptoms of hyper- and hypoglycemia, "Yeah your blood sugar could be low or high and you're sitting here struggling to keep up and they just, they don't have the symptoms. They don't understand what it feels like." A female participant identified situations in which their peers without T1DM, encouraged them to

disregard their diabetes management needs in lieu of participating in a group activity. “And sometimes they're going, going, going and, like, ’Guys, I need to stop and sit down for a minute.’ Because you're, like, shaking.”

One female participant expressed guilt over making peers without T1DM cater to their management needs, “You don't want to make them wait.” One male participant admitted to a similar situation when younger, “And whenever I would be out doing whatever-- playing, fishing, any of that-- whenever I felt slightly off and it was just us, they would make it so that it-- they’d try to convince me that it wasn’t that big of a deal so that we could all continue staying outside, doing whatever we were doing, instead of actually trying to take care of myself.” This male participant shrugged this behavior off, and nonchalantly added, “More often than not, I would just leave them…”

Conflicts with school nurses. According to the female participants, school nurses did not consider individual nuances of independent self-management of T1DM. “They don't know me. They don't know how I feel, and they don't take that [her individuality] into account. It's like, ‘Yeah, my thing [glucometer] says I'm 83. But I feel okay.’ Or ‘My thing [glucometer] says I'm 105, but I can feel myself [blood glucose levels] starting to drop.’ It's like they [the school nurses] don't know that and it's like they're either pulling me out of class saying, ‘You're just trying to miss whatever class.’ Or they're forcing me to sit there [in the nursing office missing class]. And it's never what I want to do [to independently self-manage her T1DM].” The female participants were unhappy with their experiences of independent self-management being disregarded but also felt forced to comply with the school nurse’s orders.

One female participant stated that her school nurse would sometimes, “care and like, sometimes she don't. So, like, I'll [blood glucose levels will] be like 300s [mg/dl], right, and she's [the school nurse is] supposed to call my mom, but she doesn't. And that kind of irritates me. So I'll step out in the hall and I'll call my mom.” This female participant gives up on trying to argue with the school nurse. “It's like, call my mom on the phone and you can talk to her. I'm going back to class because you're making me miss two periods [of classes] for nothing.” The tug of war between the self-management rules of the participant’s parent and the self-management rules of the school nurse inhibit the participant’s independent self-management.

Female adolescents agreed that they would prefer more freedom in independent self-management in school but are restricted by the school nurses. One female participant stated, “I wrote [logged] my stuff [blood glucose levels] down. And it's like now… we're in high school… we need to have a little bit more freedom [from the rules of the school nurse] sometimes.” Some female participants were angered by their school nurses’ interfering with their independent self-management of T1DM, one female participant stating, “I'm doing what I know is right. I've been diabetic this long. I don't need school nurses helping.” Two female participants were compelled to “Tell them [the school nurses] they don’t matter… Tell them that it's not their body” and highlighted “their [the school nurse’s] arrogance.”

One female participant stated that resistance to complying with the procedures of the school nurse was shared by her peers with T1DM in her school, “And none of the diabetics go to the nurse. The nurse doesn't care. Nobody writes their blood sugars down.” Many female participants perceived the restrictive and rigid behaviors of the school nurse as “controlling,” with one female participant stating, “My school nurses are controlling and it's like, ‘You are not

my doctor on this and you're not me.' It's like we just need to take a step back and think about everyone's place in our lives."

One female participant suggested they needed "to teach… to educate… About beliefs that they [people ignorant to T1DM] actually believe are true and they just don't know and are wrong that you can tell them about." However, another female participant asserted teaching some people is fruitless stating, "Because even if you try to teach someone who doesn't want to be taught, it's not going to work." Another female participant supported this sentiment by stating, "If they don't want to help you, they're not going to."

Difficulty navigating the healthcare system. The data from this study described the difficulties participants had navigating the healthcare system. These difficulties related to poor interpersonal relationships with healthcare providers and interference with the participants' access to the healthcare system by gatekeepers. Female participants perceived healthcare professionals who were judgmental or who did not communicate well as inhibitors of independent self-management. Gatekeepers included individuals who the female participants perceived blocked them access to the necessary medication and supplies to independently self-manage T1DM. All participants were also able to identify the injustice of lack of financial resources in obtaining insulin, diabetic supplies, and health insurance.

Poor interpersonal relationships. Some female participants did not experience a positive relationship with their providers. One female participant claimed that their provider did "nothing" to assist them with independent self-management of their T1DM. Some female participants were bothered by their providers focus on their parents during visits. "My endocrinologist doesn't talk to me, she talks to my mom. And I feel like I'm old enough where I

should at least be considered into the conversation, you know. It's my body, too, and I feel like I should get to address how I feel about what you're [the endocrinologist is] doing and the changes you're making."

One female participant thought she was not being listened to, and unfairly judged because of misinformation. "My mom signed me up for [mental health] therapy and then the doctor was like, 'Well, does she go to counseling or anything? My mom was like, 'No.' I was like, "Mom, you've literally signed me up. I go to therapy every other week.'… let me talk. I'm old enough to express my own feelings." This participant's response to the estranged relationship with their healthcare provider was to "literally sit there and, I pout. I sit there and just don't talk." Poor communication by her healthcare provider alienated the participant and cut off an opportunity to teach the adolescent independent self-management behaviors.

Participants pondered the differences between the pediatric and adult healthcare systems. One female participant stated, "I feel in pediatrics they kind of treat you more like a child almost. Where in adult … you do what you have to. But if you're not managing it [your blood glucose levels], that's kind of on you." Another participant agreed, stating if their "A1C was high it would be, like, 'Oh, you need to do it for yourself. Do it so that you don't get sick.' Where in pediatrics, they're…almost like that nagging parent..." Participants perceived the adult healthcare system as expecting the individual with T1DM to take full responsibility of independent self-management, and without care of the individual themselves.

One female participant who was seeing an adult endocrinologist stated "I feel like he does not care at all. It's just, it's so different from pediatric… my appointments with him are five minutes and he just asks me what I do for Lantus [long acting insulin dosing], what I do for

NovoLog [short acting insulin dosing], gives me the HbA1c and then just changes something and then I leave." All other participants did not have much experience with adult healthcare providers but made assumptions based on of how they foresaw their transition to adult healthcare would be.

One male participant projected, "I don't think they'll care as much, because now you're an adult and you should be able to take care of it by yourself," and another male participant added, "you should already know what you're doing. So, they kind of just check your numbers, make sure you are doing something right or see what they need to change. But, other than that, they kind of just let you go out and do whatever you're supposed to do." One male participant did not think adult healthcare providers would be as forthcoming as pediatric providers with providing the educational resources of independent self-management, "they might expect you to already know the information."

***Gatekeeper*s.** The data revealed the lack of healthcare access to insulin, healthcare insurance, medical supplies, nutrition and healthcare providers inhibitors of independent self-management of T1DM. Several female participants had complaints regarding their durable medical supply companies. "You call them [the durable medical supply company], they tell you they won't talk to you because you're a minor when you're the patient just trying to order yourself something because you know you need it." "We're supposed to be responsible but then we can't take care of ourselves because of that [being unable to speak on their own behalf in order to obtain their supplies]."

One female participant shared an experience with her durable supply company that delivers her insulin pump supplies. "'I can't talk to you because you're 16.' I was like, 'I'm the

patient. I'm telling you, I need this stuff within the next few days. My mom's at work. She needs to work. I just need to reorder something.' They're like, 'We can't give you the information.'" The female participants that had experience with dealing with their durable medical supply companies regard their customer service as "terrible," "awful," "rude," and "if they even answer," say that "they're not responding" to their needs.

Although participants were not immediately concerned with access to health insurance, insulin and healthcare providers, most participants shared knowledge of individuals with T1DM have significant difficulties with obtaining insulin, obtaining health insurance and maintaining access to proper nutrition. One male participant stated, "From time to time, you'll hear a story about someone who is unable to get access to insulin just because of financial situations, but I think being at this camp, you know that we're blessed enough to be able to afford what we need medically." The prospect of not having adequate resources to sustain independent self-management of T1DM was concerning to participants.

Another male participant reflected on his present family support system not being able to assist him in the future if he did not have the financial resources to independently self-manage his T1DM. "Because insulin's, what, $300 a vial or so? Yeah, that's way too much, considering it's something we need to live, I don't think it should be $300. That's not a 'move it from my parents' account to mine [type of situation]'" In addition to insulin, one male participant considered the need for adequate nutrition and quick access to carbohydrates. "Your blood sugar shouldn't be dependent upon your access to food."

Finally, some female participants were affected by staff turnovers and shortages of endocrinologists in their area. One female participant stated, "I like the doctor I had and then he

left me, and I haven't liked anybody since." Another stated concern over her endocrinologist leaving her group practice, "M my doctor's really sweet, very nice, always wanted to help me. And she would do everything in her power to help me and that was great. But now she's gone, and I don't know who I'm going to get next." For another participant, the endocrinologist she was seeing who was relocating was in a solo practice which meant that she and her mother needed to search for a new endocrinologist on their own. "We, me and my mom were trying to go to adults [endocrinologist], but we called a couple different ones [endocrinology offices] and none of them will take me since I'm 16 and I'm not 18 yet. None of them will take me."

Only one female participant had experience with telemedicine, "We do telemed, which is basically a video chat one and I feel like that might help if it was more face to face." The participant thought that telemedicine enabled more communication with and focused more on her parent than herself.

Summary

Through an iterative process, an overarching theme that best described this study emerged: *"Sorry, I have diabetes….it [T1DM and T1DM self-management] has shaped me into who I am"* (Table 8). Three domains emerged, which included: *The self-management behavior skills required for the adolescent with T1DM during transition from dependent to independent T1DM self-management, Facilitators of everyday participation in self-management behaviors for adolescents with T1DM,* and *Inhibitors of everyday participation in self-management behaviors for adolescents with T1DM*.

Three categories describe the first domain, *"The self-management behavior skills required for the adolescent with T1DM during transition from dependent to independent T1DM*

self-management." These categories included *Preparation & Knowledge, Responsibility*, and *Self-advocacy*.

Two categories describe the second domain, "*Facilitators of everyday participation in self-management behaviors for adolescents with T1DM*." These categories included *Community influences* and *Navigating the healthcare system*. Three subcategories fell under *Community influences* which included *Family, Peers* and *Extra-community*. Three subcategories fell under *Navigating the healthcare system* which included *"Not making a big deal out of it", Technology allows more "freedom,"* and *Interpersonal relationships with healthcare providers*.

The data revealed three categories, which reflected the third domain, "*Inhibitors of everyday participation in self-management behaviors for adolescents with T1DM*." The three categories include *Lack of self-accountability, Lack of community Support,* and *Difficulty navigating the healthcare system*. The first category, *Lack of self-accountability*, branched into four subcategories: *Demands of T1DM self-management, Embarrassment, Blaming*, and *Lack of self-responsibility*. Four subcategories also evolved from the second category, *Lack of community support*: *Lack of family support, Peers who "don't understand,"* and *Conflicts with school nurses*. The third category, *Difficulty navigating the healthcare system*, branched into two subcategories; *Poor interpersonal relationships*, and *Gatekeepers*.

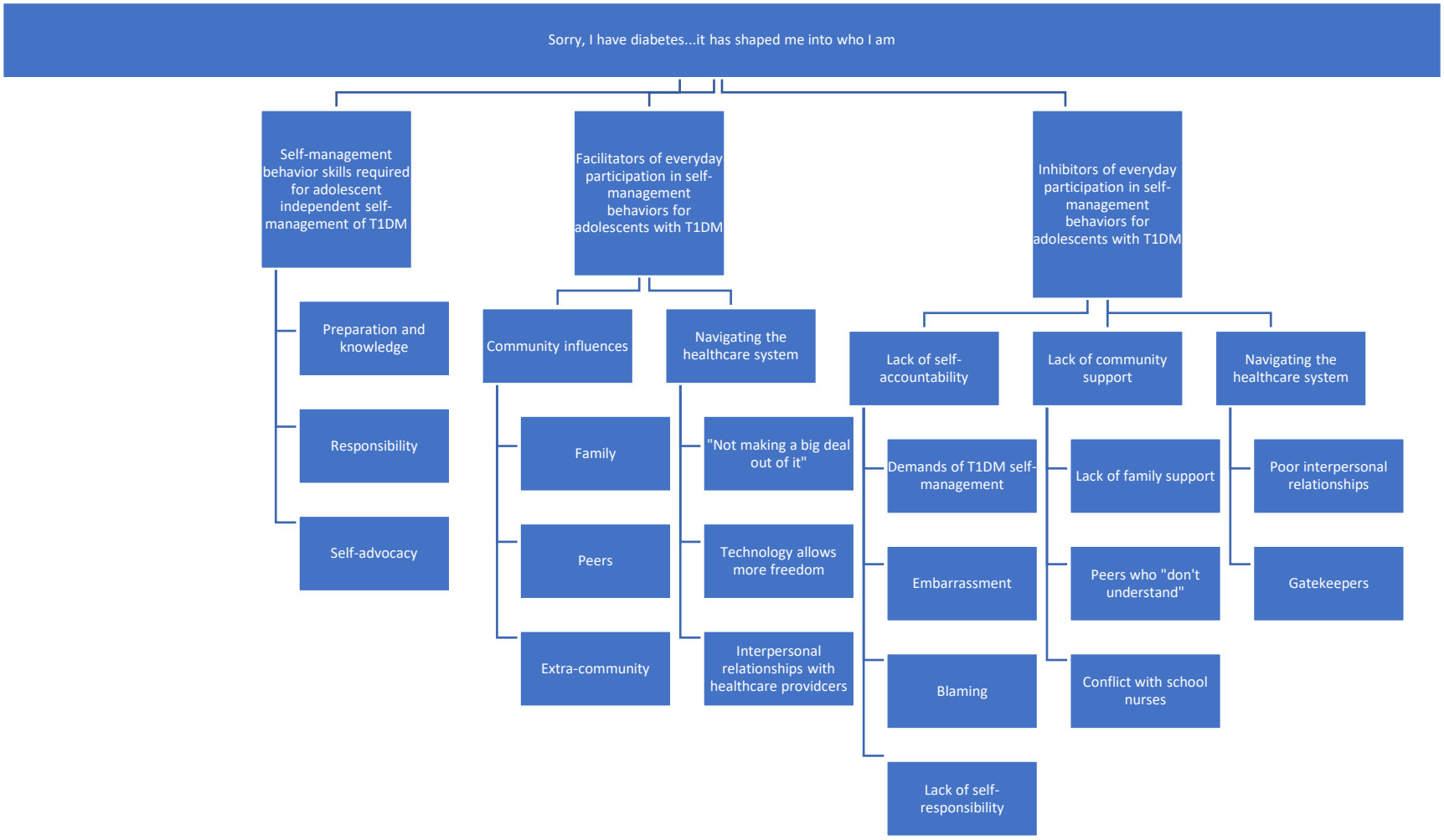
Conclusion

"Sorry I have diabetes…it [T1DM and T1DM self-management] has shaped me into who I am" sets the theme to the present study in which the self-management behavior skills, and the facilitators and inhibitors of independent self-management of adolescents with T1DM is described. The domains, categories, and subcategories are supported by the unique perspectives

of the participants. Qualitative content analysis was used to develop a taxonomy that represent the a priori inductive data analysis (Table 8).

The participants in this study accepted themselves and accepted carrying the diagnosis of T1DM. Independent self-management is very challenging for the adolescent with T1DM. They must understand the effect of T1DM on their body, practice the behaviors and accept the responsibility of independent self-management of T1DM, and advocate for their independent self-management needs within their community. This was challenging for the adolescent with T1DM who lacks community resources, and has difficulty navigating the healthcare system. At times participants were overwhelmed by the demands of independent self-management. At times participant independent self-management behaviors were inhibited by blaming their lack of ability to independent self-management on causes outside of their control, embarrassment over the disease process and independent T1DM self-management requirements or refusing to take responsibility of their independent self-management behaviors. Some participants lacked community resources and had poor relationships with their healthcare providers. Despite the frustration, anger, and distress expressed by the participants, they were still able to find strength in their community support systems, learn from their healthcare providers, practice responsible behaviors, utilize technology in attempts to improve glycemic control and self-advocate their needs within their communities, and simply not make a big deal out of it.

TABLE 8. *Taxonomy of data analysis.*



CHAPTER 5: DISCUSSION

Conclusions

The purpose of this chapter is to compare the findings in this study to those of current literature. This study provided insight on the facilitators and inhibitors of independent self-management for adolescents with T1DM. Overall, no gender-based patterns were identified in the data. This study addresses several of the knowledge gaps identified in a literature review which includes the psychological behaviors of the adolescent that impacts independent T1DM self-management (Polfuss et al., 2015), the reasons adolescents with T1DM are unable to stay on track with the responsibilities of self-management (Babler & Strickland, 2015), some of the internal and external motivators of independent self-management, the influence of technology on independent self-management (Los et al., 2016; Babler, 2015; Sheehan et al., 2014), the mental health needs of the adolescent including diabetes distress, the relationships and interdependence between the adolescent, parent, and providers (Castensøe-Seidenfaden, et al., 2016; Polfuss et al., 2015; Sullivan-Bolyai et al., 2014), and the community support needs of adolescents with T1DM.

Discussion of Findings for Research Question 1: What are the Self-Management Behavior Skills Required for the Adolescent with T1DM During Transition from Dependent to Independent T1DM Self-Management?

Adolescents with T1DM must have adequate knowledge of T1DM etiology and management requirements, such as blood glucose monitoring, taking insulin, and maintaining proper nutrition and activity levels, to be able to engage in independent self-management of T1DM (Bomba et al., 2017; Aloha & Groop, 2013). Transitional programs that increase

knowledge and self-efficacy have been shown to facilitate smooth transitions to independent self-management of adolescents with T1DM (Campbell & Biggs et al., 2016).

There is more to glycemic control than physical tasks and empirical measurements of glycemic control, such as emotional adjustments to the disease, decision-making skills, co-morbid disease management, and establishment of social networks (Radovick & Misra, 2018; Babler & Strickland, 2015; Ahola & Groop, 2013; Schilling et al., 2002). To become independent with self-management, the adolescent with T1DM must develop an understanding of the disease process and how T1DM personally affects their bodies to educate their communities and take responsibility for the behaviors of T1DM management.

A health-illness transition of adolescents with T1DM from dependent to independent self-management requires self-advocacy to establish safety networks that support independent self-management within their communities. Adolescents with T1DM evaluate the role of individuals in their community and, using creative reflection and abstract thinking, consider the importance of each community member's role in assisting them with independent self-management of T1DM.

The developmental transition self-identity formation in the adolescent with T1DM is supported by self-advocacy behaviors. This developmental transition converges with the health-illness transition of the adolescent with T1DM as they accept the responsibility of independent self-management and merge independent self-management behaviors within their new personal value system. Self-advocacy further served to establish an environment in which participants perform independent self-management.

Babler & Strickland (2016; 2015) proposed maintaining a routine to integrate independent self-management behaviors into everyday life was a way of normalizing Independent self-management in their lifestyle. In this study, normalizing was demonstrated through participant behaviors of responsible, independent self-management. Responsibility occurred concomitantly with self-advocacy. Participants agreed that maintaining a routine influenced responsible, independent self-management behaviors, such as changing their pump sites on time, setting alarm clocks to remember to take insulin, preparing and carrying their backpack with needed supplies, and maintaining a routine.

Discussion of Findings for Research Question 2: What Facilitates Everyday Participation in Self-Management Behaviors for Adolescents with T1DM?

The perceptions of success in the transition to independent self-management differ between parents and adolescents with T1DM (Joley, 2015). Current literature highlights the difficulties parents have negotiating the shift from the role of primary caregiver to supportive resource network for their adolescent with T1DM. (Babler & Strickland, 2016; Polfuss et al., 2015; Sheehan et al., 2014; Sullivan- Bolyai et al., 2014). This study described the gradual shifts in roles of and relationships between adolescents with T1DM and their parents from the adolescent's perspective of the transfer of responsibilities of self-management.

Adolescents with T1DM experience the developmental task of exploring and developing a personal value system. This new value system is often separate from the value system held by their parents' (Newman & Newman, 2011; Becht et al., 2010; Brown et al., 2005). However, adolescents with T1DM are required to adhere to ADA guidelines in their health-illness transition from dependent to independent self-management. Routine behaviors become part of

the lifestyle of the adolescent with T1DM (Babler & Strickland, 2016; 2015). In this study, the adoption of the standards of T1DM care within their evolving value system and self-identity facilitated participants' independence in T1DM self-management.

The decreasing physical, psychological and psychosocial conflict between the parents and the adolescent with T1DM during the transition to independent self-management improves health outcomes (Babler & Strickland, 2016; Joley, 2015; White et al., 2015). Strong relationships with parents, self-confidence and parental trust of the adolescent with T1DM is associated with improved glycemic control (Bomba et al., 2017; Castensøe-Seidenfaden, & Teilmann et al., 2016; Beal et al., 2016; Egan et al., 2015; Babler & Strickland, 2015; Joley, 2015; Polfus & Babler et al., 2015; Hilliard et al., 2014; Rollo et al., 2014; Sheehan et al., 2014; Sullivan-Bolyai et al., 2014). Further, willingness to accept assistance from others (Babler & Strickland, 2015) and the use of parents and other family members as resources (Ersig et al., 2016) facilitates independent self-management.

The participants' perceptions of parental support and involvement in their self-management of T1DM vacillated in a delicate balance as they moved from dependent management to being equal partners in self-management, and finally to independent T1DM self-management. Parental trust in participants' abilities to perform independent self-management boosted self-confidence. The use of parents as safety nets to troubleshoot difficult situations improved outcomes of independent self-management, such as improved glycemic control, community advocacy, and navigating the healthcare system. Parents served as a resource during the day to troubleshoot difficulties with independent self-management and as back up monitors of participants' CGM alarms through the night. Since independent self-management was more

difficult at night, parents who were there to help in case of an emergent or urgent situation and the additional assistance was appreciated.

Higher HgA1C levels have been found in adolescent females and are associated with both hormonal and behavioral causes (Nirantharakumar, Toulis, Thomas, & Narendran, 2018; Carlsen et al., 2017; Agha, Alafif, & Abd-Elhameed, 2015). In this study, the willingness to accept and receive family support differed between genders. Male participants in this study were found more likely to accept and receive family support to troubleshoot their independent self-management. However, female participants thought that parental involvement and assistance was greatest in the early years of T1DM diagnosis and diminished as they got older. Both perspectives were without regard to the age of onset of T1DM- whether diagnosed during childhood or adolescence.

Peer support and the adolescent's use of peers as resources has been found to facilitate independent self-management of T1DM (Bomba et al., 2017; Ersig et al., 2016; Babler & Strickland, 2016; 2015; Joley, 2015; Helgeson et al., 2014; Hilliard et al., 2014). The benefit of peers with T1DM is the engagement in a commiserate understanding of the demands of T1DM, both the disease symptoms and management (Bomba et al., 2017; Fernandez et al., 2014). Although participants made a distinction between positive influences of peers with and without T1DM on independent self-management of T1DM, peers without T1DM were not as readily accessible as their peers without T1DM.

Current literature supports the positive benefits of peer support groups (Fernandez et al., 2014). Female participants in this study clarified that "not just any diabetics" were considered supportive of independent self-management. The desire to engage peers with T1DM to support

their independent self-management was also dependent on their similarities in developmental level and their ability to develop a bond of friendship. Female participants attempted to troubleshoot the limitations of geographical distance to maintain their relationships outside of the summer camp setting, but had difficulty presenting resolutions.

Peers without T1DM played a significant part in the participants' independent self-management. This study found several qualities of peers without T1DM that facilitated independent self-management. These qualities included an understanding the significance of T1DM in the participants' life, higher levels of "awareness" of T1DM, T1DM self-management, and signs and symptoms of hypo- and hyperglycemia, and willingness to help the participant achieve success in independent self-management.

This study provided a further understanding of the extra-community facilitators of independent self-management from the perspective of adolescents with T1DM. Participants' extra-community consisted of the teachers, coaches, and nurses within their high schools through which participants self-advocated and developed safety nets. Participants used extra-community safety nets throughout their school day and as needed for urgent or emergent resources.

Schools facilitated independent self-management through the integration of T1DM education in their curriculums. Two female participants described dynamic, positive environments built into school curriculums, during which the participants were able to self-advocate their independent self-management needs. Also, these participants were provided a venue to engage in the education of the public and increase the general knowledge of T1DM within their school community.

Higher confidence levels, emotional preparedness, improved coping behaviors, and positive outlooks are associated with positive transitions to independent self-management (Babler & Strickland, 2016; Beal & Riddle et al., 2016). Further, positive perceptions of healthcare, increased responsibility for healthcare needs, communication about the healthcare transition, and higher levels of health literacy are associated with a successful transition to independent self-management (Beal & Riddle et al., 2016). Higher comfort levels of the participant with the transition process, the use of technology, and positive interpersonal relationships between the adolescent with T1DM and the healthcare providers facilitated participant navigation of the healthcare system. Participants identified communication, trust, and respect between themselves and their healthcare providers as facilitators of independent self-management.

This study supported current literature, finding that the use of CGMs facilitates independent self-management in adolescents with T1DM (Los et al. 2016). CGMs allowed the participants more "freedom" from the tasks of fingersticks and made glucose monitoring much easier. CGMs served as both a personal alarm system to monitor and treat blood glucose levels and assisted their community safety networks/back-ups in blood glucose monitoring.

Discussion of Findings for Research Question 3: What are the Barriers to Participating in Everyday Self-Management Behaviors for Adolescents with T1DM?

Frustrations with the significant demands of T1DM management inhibited participants' independence with self-management. Poor self-accountability, inadequate knowledge, inadequate preparation, and poor communication of self-management needs inhibited participants' abilities to self-advocate. T1DM self-management and individual competencies are

significantly impacted by socioeconomic inequality, with low-income disproportionately affected and at high risk for disease-specific complications (Long, Field, Armstrong, Chang, & Metlay, 2010). Adequate access to insulin, health insurance, and nutrition was not of immediate concern to the participants. However, the participants did recognize that they were "blessed" to be financially secure but agreed that lack of access to the medications, nutrition, and supplies needed to manage T1DM is unjust, and something that they would have to consider in their future.

The reasons that adolescents with T1DM are unable to stay on track with the responsibilities of independent self-management remain elusive (Babler, 2015). Some female participants had difficulty integrating ADA guidelines of independent self-management into their personal value systems. This created friction within the members of their communities and society. The reasons for their inability to consistently sustain the motivation to perform these independent self-management responsibilities included lack of self-accountability due to the demands of T1DM management, embarrassment over carrying the diagnosis of T1DM and the T1DM needs, finding blame of poor health outcomes outside of themselves and lack of personal responsibility. Lack of community support, which included support from family, peers, and school nurses, also interfered with participants' ability to stay on track with the responsibilities of independent self-management.

This study highlighted the impact of co-morbidities, such as Celiac disease, sleep disturbances, sleep apnea, and mental health disorders, as inhibitors of independent self-management. Overall, female participants expressed more difficulties with all co-morbid conditions than male participants. Only one male participant confirmed carrying a diagnosis of

depression. Female participants agreed that society, in general, was becoming more accepting of mental health issues and acknowledged that management of mental health comorbidities is necessary for independent T1DM self-management. However, the clinical manifestations of depression suppressed their desire to independently self-manage T1DM. Further, female participants thought that distress or depression was inevitable when carrying a diagnosis of T1DM.

In support of current literature, this study identified overbearing parents and family members, as inhibitors of independent T1DM self-management (Babler & Strickland, 2016; Castensøe-Seidenfaden & Teilmann et al., 2016; Ersig et al., 2016; Hilliard et al., 2016; Polfuss et al., 2015). Female participants expressed frustration with family members who lacked the knowledge of T1DM and T1DM self-management, yet imposed their authority nonetheless. Overall, the female participants expressed more turbulent relationships with their parents than male participants.

The role of the nurse in the transition process of the adolescent with T1DM to independent self-management is to provide disease etiology and management education and establish an equal partnership with the adolescent with T1DM (Babler & Strickland, 2015; Joley, 2015; White et al., 2015). This study found that control over the behaviors of independent self-management was at the core of a power struggle between adolescents with T1DM, their parents and school nurses. Control over the behaviors of independent self-management was influenced by the degree of trust and respect amongst the school nurse, the participant, and the participant's mothers.

Peers without T1DM required more education than peers with T1DM. Although bullying behavior was perceived by the participants in this study to dissipate in adolescence, for some participants, a unique form of peer pressure by peers without T1DM replaced bullying behaviors. Peers without T1DM pressured some participants to disregard T1DM self-management behaviors because it interfered with their social activities. In female participants, this led to feelings of guilt and embarrassment.

In this study, disruptions in relationships with healthcare providers, insurance companies, pharmacies and durable medical supply companies interfere with independent self-management. Healthcare provider access was limited by provider turnovers and shortages. Telemedicine reduced focus on provider-adolescent communication per the one female participant who participated in telemedicine. Female participants described restrictions in their ability to communicate with the durable medical supply provider and insurance companies because of their age.

Transitional programs must consider interventions that promote self-accountability in the adolescent with T1DM and teach the skills of diabetes management. Discussion of transition from pediatric to adult healthcare should be initiated early in adolescence by the adolescent's community and healthcare networks (Egan et al., 2015). In this study, only one female participant had transitioned to adult healthcare at the time of the study. All other participants made assumptions regarding transitioning to adult healthcare.

Implications for Clinical Practice

In 2002, the American Academy of Pediatrics (AAP), American Academy of Family Physicians, and the American College of Physicians (ACP) responded to the difficulties of a

growing number of adolescents with special health needs transitioning from pediatric to adult healthcare (Lemly et al., 2013; American Academy of Pediatrics (AAP), American Academy of Family Physicians, American College of Physicians, &American Society of Internal Medicine, 2002). They developed guidelines for adolescents age 12 and older with special health needs transitioning from pediatric to adult healthcare (Lemly et al., 2013; AAP et al., 2002). The guidelines consist of the six core outcomes: 1) the development of transition policy, 2) enrollment of youth in a transition registry to monitor the preparation, 3) planning and outcomes of transition, 4) transition preparation, 5) transition planning, transitions and transfer of care, and 6) transition completion (Lemly et al., 2013).

The primary goals of the transition guidelines for adolescents with special health needs are to 1) ensure the smooth, uninterrupted transition of the adolescent from pediatric to adult healthcare services, 2) incorporate specialized knowledge of adolescent transitional preparation into physician practice training and certification, 3) improve the portability of medical records for smooth collaboration between pediatric and adult providers, 4) develop and maintain a transitional plan of care for all adolescents with special healthcare needs starting at the age of at least 14 years, 5) ensure the provision of primary and preventative adolescent healthcare services to and recognizing the increased service needs of the adolescent with social healthcare needs, and 6) ensure the provision of affordable health insurance to adolescents with special healthcare needs from adolescence through adulthood (AAP, 2002).

The American Diabetes Association (ADA) publishes and updates current clinical practice standards of diabetes care. Chapter 12 of the publication is devoted to standards of care for children and adolescents with diabetes. Transition planning for the adolescent with T1DM

emphasizes some of the six core outcomes discussed above, with a specificity of diabetes-related health needs. The ADA provides recommendations on 1) diabetes self-management education and support, 2) school and child care, emphasizing psychosocial issues in youth, 3) preconception counseling, 4) diagnostic challenges associated with obesity and distinguishing between T1DM and type 2 diabetes, 5) glycemic control, 6) comorbidity of autoimmune diseases, 7) management of cardiovascular risk factors including discouragement of smoking in youth, 8) microvascular complications and 9) the transition from pediatric to adult care. Recommendations for the transition from pediatric to adult healthcare include the initiation of transition planning by pediatric providers early in adolescence and provision of transition support and resources by both pediatric and adult healthcare providers (ADA, 2018).

Although no consensus exists that specifies variables to describe health vulnerabilities, many researchers agree that this complex concept requires further explanation (Sampselle, 2007). Adolescents with T1DM may be considered vulnerable populations, due to their experience of health disparities resulting from a lack of physiological, psychosocial, psychological and economical resources and increased exposure to the health risks of poor glycemic control (Flaskerud & Lesser et al., 2002; Anderson & Olnhausen, 1999). The vulnerable populations conceptual framework proposes a relationship between resource availability, relative risk, and health status (Figure 3).

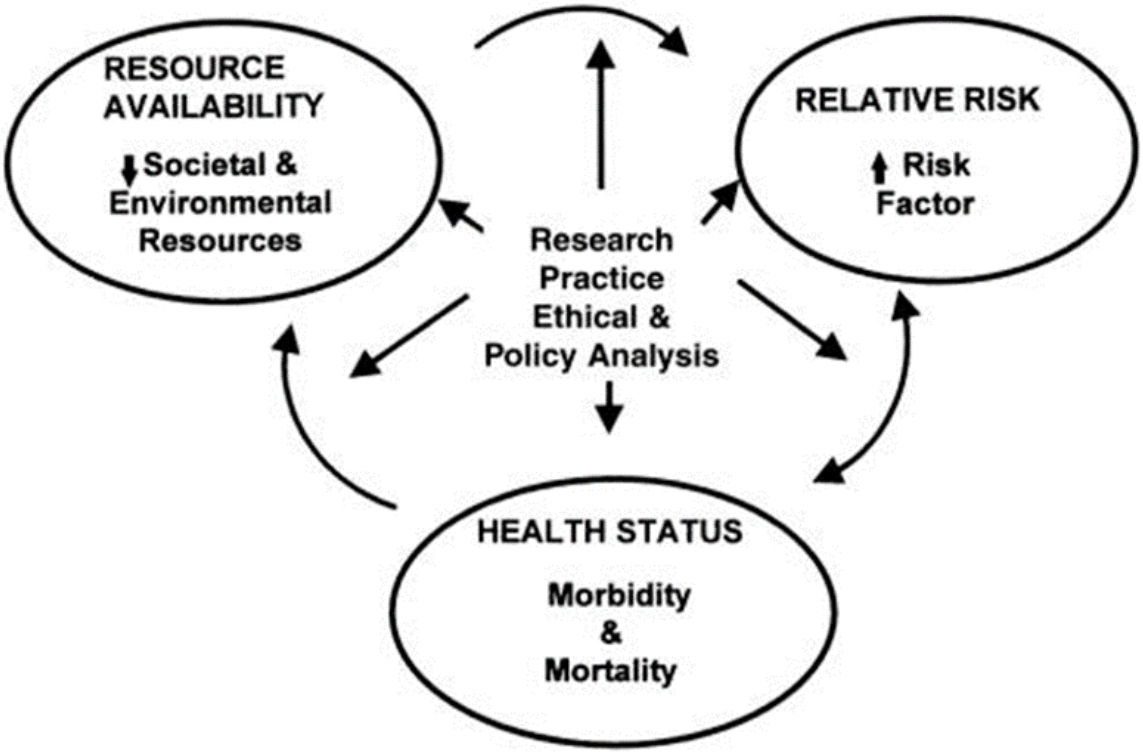


FIGURE 3. Flaskerud and Winslow's (1998) vulnerable populations conceptual model for research and practice (Flaskerud & Lesser et al., 2002).

According to Flaskerud and Winslow's model (1998), resource availability is the availability of socioeconomic and environmental resources (Flaskerud & Lesser et al., 2002). Relative risk is the ratio of the risk of poor health among groups such as adolescents with T1DM with limited access to resources and high exposure to risk factors as compared to similar groups with sufficient social and environmental resources without exposure to risk factors (Flaskerud & Lesser et al., 2002; Aday, 1994). Disease prevalence and morbidity and mortality rates reflect the health status of a community, defined by pathophysiologic and psychopathologic processes and changes (Flaskerud & Lesser et al., 2002).

Individual or group characteristics or challenges to an individual's integrity constitute health vulnerabilities (Spiers, 2000). Collective risks that lead to costly and inferior health outcomes and failure to take measures to protect individuals from unusual risks contribute to the creation of a vulnerable population. Descriptive, multivariate, and interventional nursing studies explain the relationships between the vulnerable population and health risk (Flaskerud & Lesser et al., 2002). Nursing research must continue to evolve, emphasizing community and population-driven models and interventions that enact changes in health outcomes and advance health policy to avoid increasing vulnerability in high-risk populations such as adolescents with T1DM (Flaskerud & Lesser et al., 2002).

Inadequate social support and relationships, low levels of self-control and self-esteem, and social power perceptions contribute to high-risk behaviors (Shi et al., 2008). Social support- the positive interactions and supportive behaviors that underlie an individual's social relationship such as information, emotional comfort, and practical assistance provided by family, friends, neighbors, community organizations, or neighborhoods create the social networks that assist individuals in navigating and coordinating available sources of support (Koetsenruijter, van Lieshout, Lionis, Portillo, Vassilev et al., 2015; Hupcey, 1998). Familial, occupational, community, and institutional social support networks increase access to social capital- the quantity and quality of an individual's interpersonal social relationships, which results in improved self-management behaviors by improved access to care (Vest, Kahn, Danzo, Tumiel-Berhalter, & Schuster et al., 2013; Shi et al., 2008). Social capital broadens the concept of population health by expanding beyond the aggregated characteristics of individuals within a

community and focuses on the quantity and quality of interpersonal relationships (Veenstra, 2003).

Social support requires a balance between and understanding of an individual's perception of support, the intentions of the supporter, the perception of reciprocity or the exchange of support, and the social networks that define social support (Hupcey, 1998). The perception of help depends on the timing and type of support provided. Motivation to support another individual can be altruistic (Hupcey, 1998). However, skepticism of other factors like a social obligation or desire for the return of favors may influence individual perceptions of support and the satisfaction of the recipient (Hupcey, 1998).

Low stocks of social capital and community resources result in poor health outcomes (Reeves, Blickem, Vassilev, Brooks, Kennedy et al., 2014). An increased focus on the social network and community resources may lead to improved, cost-effective long-term health outcomes (Reeves & Blickem et al., 2014). Social networks may be a positive influence on behavior or perceived as demanding and stressful, depending on the social context of support (Hupcey, 1998). Cultural and social personalities and roles, psychological factors, coping history, history of supportive relationships and outcomes, and ability to assess resources influence an individual's ability to request and accept support (Hupcey, 1998). Therefore, the goal of social support is to achieve a balance between the views of both the recipient and provider of aid.

Social support is categorized based on the simple concept of provider and recipient characteristics and perceptions (Hupcey, 1998). Those that provide social support will balance the recipient’s needs with their judgments (Hupcey, 1998). The provider must feel appreciated in

efforts, but the perception of support influences this appreciation. The inability of the provider to accurately assess the needs of the recipient or use of excessive requests of social support by the recipient may contribute to burnout and premature withdrawal of support (Hupcey, 1998).

The dynamic process between the provider and recipient of social support can be fragile. For example, the adolescent with T1DM may view their parents' reminders to check their blood glucose levels as supportive. On the other hand, these same reminder's the adolescent may see these same reminders as nagging or overbearing such as the female adolescent who referred to her mother as "two-sided." This perception of nagging may affect the motivation of the adolescent with T1DM to be independent with T1DM self-management and can delay the transition process to adult health care (Castensoe-Seidenfaden, 2016; Babler & Strickland, 2015; Fernandes, O'Sullivan-Oliveira, Landzberg, Khairy, Melvin et al. 2014; Hilliard et al., 2014).

There has been a growing focus of the social determinates of health and the positive effects of social capital on health in research and literature (Farajzadegan, Jafari, Nazer, Keyvanara, & Zamani, 2012). Social capital is the membership to a social group or social network which stresses trust and reciprocity and secures the positive benefits of productivity and economic well-being (Hawe & Shiell, 2000). The integration of and autonomy of group members and their relationships with individuals and the community outside of the group are used to promote the well-being of the individual (Hawe & Shiell, 2000). The durability and investment of time and money to sustain a healthy social support system are crucial to building and maintaining the social capital framework of trust and obligation (Hawe & Shiell, 2000).

Opportunities for individuals to pursue health and the choices they make within the confines of their social structure affect their ability to access social capital (Jones, Lee, Phillips,

Zhang, & Jaceldo et al., 2001). Nursing research must focus on the relationships between adolescents with T1DM, their communities, and their health risks. Improved communication between the AT1DM, parents, and pediatric and adult healthcare providers involved in independent self-management transition can prevent the poor health outcomes that result from gaps in care (Bomba et al., 2017; Egan et al., 2015; Joley, 2015; Rollo et al., 2014; Hilliard et al., 2014; Sheehan et al., 2014; Kime, 2013; Lotstein et al., 2013; Lyons et al., 2014). Increasing the satisfaction of the adolescent with T1DM with a peer, parental, and provider support during the transitional process may improve adherence to disease management requirements and long-term outcomes (Maiorino et al., 2014).

Human capital, social connectedness, social status, and environmental conditions categorize the health disparities related to the developmental transition of the adolescent with T1DM from dependent self-management to independent self-management (Flaskerud & Lesser et al., 2002). Adolescents are dependent upon the economic resources of their parents, and poverty has a significant impact on the disease management and outcomes of the adolescent with T1DM (Flaskerud & Lesser et al., 2002). In addition, changes in health care insurance and decreased access to disease management resources intensifies the financial instability associated with moving out of the family home (Hagger et al., 2016; Adal et al., 2015; Raymond, 2015; Wiebe et al., 2014).

There are positive correlations found between co-morbidities and other autoimmune diseases commonly found in adolescents with T1DM such as thyroid disease, diabetes distress, depression, disordered eating, and drug or alcohol addictions and elevations in HgbA1C (Hagger et al., 2016; Quinn et al., 2016; Rollo et al., 2014). This study supports the need to incorporate

the mental health needs of the adolescent with T1DM, including diabetes distress and depression into transition planning. However, feelings of isolation during the transition process, the sustainability of cognitive restructuring, goal setting and problem-solving on diabetes distress reduction is also needed to integrate into transition programs (Hagger et al., 2016; Castensøe-Seidenfaden et al., 2016; Babler & Strickland, 2015; Polfuss et al., 2015; Sullivan-Bolyai et al., 2014).

Implications for Research

Adolescents in the United States with chronic health conditions do not receive standardized, quality transitional preparation (Sawicki et al., 2017). Current research studies on the measurement of transitional programs that prepare adolescents with T1DM on the transition to adult healthcare are not consistent (Little & Odiaga et al., 2016; Schmidt et al., 2016; Chu, Maslow, & von Isenberg et al., 2015; Polfuss et al., 2015; Egan et al., 2015; Chu et al., 2015). Further, there is a lack of knowledge of determinants of successful adolescent transition to independent self-management and descriptive processes and protocols of transition to develop, monitor, and evaluate transition programs (Chu et al., 2015; Sheehan et al., 2014). Most research studies focus on the parents' and healthcare professional's perspective of adolescent transition to adult medicine, but the adolescent perspective must be valued as a competent contributor to the transitional planning process (Farrell et al., 2018; Ersig et al., 2016).

This study supports the need for transitional measurement criteria that goes beyond the numbers of glycemic control, such as HbgA1C (Sullivan-Bolyai et al., 2014). Further research must also measure the attainment of the behaviors of independent self-management identified in this study and correlate those behaviors with long-term glycemic control and disease outcomes.

Longitudinal studies are needed to evaluate the long-term effectiveness of transitional programs that incorporate the facilitators and inhibitors of independent self-management found in the present study (Farrell et al., 2018; Ersig et al., 2016; Castensøe-Seidenfaden et al., 2016).

Although most participants in this study reported discussing the transition to adult healthcare with their providers and all participants expected to transfer to adult healthcare after 18 years, variability in levels of independent self-management persisted. The correlation between early transition planning and the behaviors of independent self-management identified in the current study, such as self-advocacy, responsibility, self-accountability, community influences, and ability to navigate the healthcare system, and long-term outcomes that consider these behavioral variables requires further study. Further research is also needed on the adolescent, parental and provider knowledge of transition planning (Sawicki et al., 2017) as well as parental responses to the transition of their adolescent (Babler & Strickland, 2016).

Based on the study findings, the PI recommends several areas for further research. Recommendations include qualitative and quantitative research to understand further, 1) the social determinants of adolescent with T1DM transition to independent self-management and the unique self-management behaviors, facilitators, and inhibitors of independent self-management of subsets of adolescents with T1DM, grouped by race, culture, and socioeconomic levels, 2) the relationship between and gender differences regarding willingness of adolescents with T1DM to accept family support and independent self-management, 3) the triadic relationship between school nurses, the adolescent with T1DM and their parents, and 4) the subset of adolescents with T1DM with co-morbidities such as diabetes distress, depression and mental health issues, sleep apnea and celiac disease, and how the etiologies and management of these co-morbidities impact

the independent self-management behaviors of adolescent with T1DM. Research is also needed to develop and evaluate interventions that 1) support and strengthen the relationships between adolescents with T1DM, increase accessibility to peers with T1DM, and facilitate the bonding experience between adolescent with T1DM, 2) support and strengthen the triadic relationships between adolescents with T1DM, their parents and school nurses, 3) compare the impact of different environments through which the adolescent with T1DM can self-advocate to and educate their community on T1DM, 4) incorporate the use of technology in the community and healthcare system in which the adolescent with T1DM interacts, and 5) prepare for and prevent diabetes distress in adolescents with T1DM.

Study Strengths and Limitations

A major strength of this study was the middle range theory Meleis' Transitions Theory that informed the research questions and data analysis and built on current theoretical knowledge to inform a proposed practice level theoretical model of the transition of adolescents with type 1 diabetes from dependent to independent self-management. Application of the theory of transitions of adolescents with T1DM to independent self-management illuminated the convergence of the health-illness transition of adolescents with T1DM from dependent to independent self-management with the developmental transition of adolescents with T1DM to emerging adulthood and can be used to inform further research studies. (Figure 4).

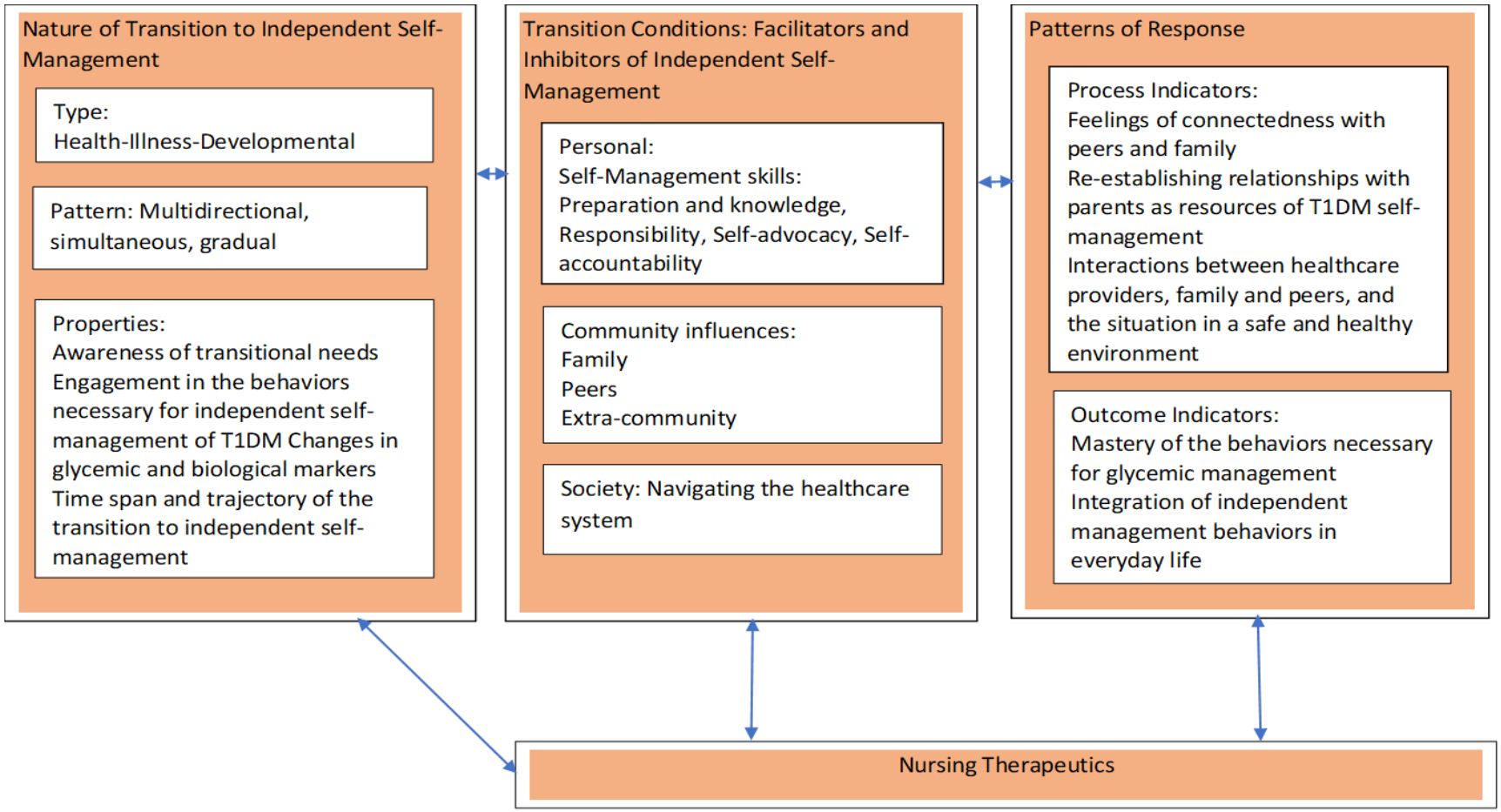


FIGURE 4. Proposed Meadows' theory of transition of the adolescent with T1DM to independent self-management

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The second strength of this study was that the camp setting might have encouraged the sharing of the perspectives of participants regarding support from peers with T1DM. Adolescents who come to camp share a desire to engage with other children and adolescents with T1DM in a camp setting. Most participants were familiar with each other, but there were also new campers who were meeting during the focus group interview. Regardless, the camp setting is one of comradery that welcomes and facilitates bonds of friendship in a safe, accepting environment.

A third strength of this study was participants' familiarity with the PI in her role as a NP at Camp Possibilities. Although the PI maintained vigilance to the potential of placing herself in a power position, the familiarity to most participants served as a strength in the development of trust between participants and PI. Participants demonstrated their trust in the PI during the discussion of T1DM support groups. The female participants balked at diabetes support groups led by adults yet were eager to continue their conversations following the interview in their cabins, even inviting the PI to attend.

Limitations of this study pertained to the demographics of the study group. The study collected limited personal data, for example we did not request the socioeconomic or mental health history of the study population. This study described the concerns of adolescents with the financial burdens of T1DM, but the participants themselves did not express an immediate concern for lack of financial resources. All the male participants stated their intent to continue onto college following high school graduation. Future aspirations were not clarified with the female participants and may have accounted for some of the differences in responses between the genders.

There was little racial diversity within the study population. One female reported a mixed-race of African-American and Caucasian and another female reported a mixed-race of African American and Latino. All other participants were Caucasian. Lack of racial diversity may have increased the likelihood of missing descriptive data.

Conclusions

The study findings support the need for further research on the implementation of developmentally appropriate transitional curriculums that begins with knowledge of T1DM etiology and management and its effects on the adolescent with T1DM. Transitional programs for adolescents with T1DM must encourage self-responsibility and teach self-advocacy skills. Transition curriculums should include the development and maintenance of healthy relationships and conflict resolution with community members including family, peers, and school personnel. Adolescents with T1DM need instruction on navigating the healthcare system and managing the gatekeepers to healthcare access. Transitional programs must promote self-accountability of the adolescent with T1DM to help them manage the demands of independently managing their T1DM and to overcome the embarrassment of the behaviors required for independent T1DM self-management. Finally, further research is needed to refine the proposed theory of transition of the adolescent with T1DM to independent self-management.

APPENDIX A:

ASSENT TO PARTICIPATE IN RESEARCH

University of Arizona
Assent to Participate in Research

Study Title: Facilitators and Inhibitors of Independent Self-Management of Adolescents with Type 1 Diabetes

Principal Investigator: Rita Elizabeth Jean Meadows, MSN, FNP-BC

You are being asked to participate in a research study. Your participation in this research study is voluntary and you do not have to participate. This document contains important information about this study and what to expect if you decide to participate. Please consider the information carefully. Feel free to ask questions before making your decision whether or not to participate.

The purpose of this research study is to find out:

1. What you think are the Type 1 diabetes self-management behaviors?
2. What are the things that might help or get in the way of your being successful in independently managing your Type 1 diabetes?

You are being asked to participate in a focus group interview that will take 60 minutes to complete and complete a demographic data form that will take approximately 5-minutes. You may stop your participation in this study at any time. There are no expected physical risks to you as a result of participating in this study. However, loss of confidentiality is a potential risk. Even though we will tell all participants in the study that the comments made during the focus group should be kept confidential, it is possible that participants may repeat comments outside the group. Although no injury directly related to the research is foreseeable, if you suffer a disease-related events such as hyper- and hypoglycemic events, or adverse behavioral, emotional or mental health events during the focus group interview, you will be provided time and healthcare resources necessary to manage the event by the Camp Possibilities healthcare staff and/or Camp Possibilities behavior support team. You will not be paid for participation in this study. You will not benefit directly from participating in this study. However, this study will contribute to current body of knowledge and may inform development of transition programs for adolescents transitioning to independent self-management.

Permission/assent forms, audio recordings, demographic forms, handwritten field notes, memos, and transcripts- a written version of the audio recordings of the focus group interviews will be uploaded, safely stored and managed in an encrypted password-protected computer during camp. The data will then be uploaded into a software system that will help analyze the data. A professional, secure and confidential transcription service based in the United States will be used to create the written transcripts from the audio recordings. All permission/assent forms will be stored in a in a locked box in the PI's private quarters during camp and until transferred to storage at the University of Arizona College of Nursing. All audio recordings will be stored on a password protected encrypted computer and will be destroyed once they are transcribed. Transcription files will also be digitally saved on a password protected encrypted

computer. Any data that reveals your name will be removed from all transcripts and forms. Fictional names may be used to match transcripts to demographic questionnaires. Data will be kept for six years after you turn 18 years old. Only the Principle Investigator (PI) and the PI's dissertation committee will have access to the data. Information collected will not be used or shared for future research studies.

Data is collected during the focus group only. You may take breaks or stop the interview at any time and may withdraw from the study at any time without any ill will; and you may continue to participate in the Camp if you withdraw from the study. Focus group interviews will be conducted in a private, vacated living room area in the healthcare staff's living quarters at Camp Possibilities. Interviews will be conducted before camp orientation to minimize disruption of camp activities. Upon completion of the focus group, you will return to Camp activities.

If you are withdrawn from the focus group due to disruptive behavior or illness, you will be counted as an enrolled participant and the data that is collected up until point of withdrawal may still be used. If you are withdrawn from Camp Possibilities attendance before the focus group interviews begin, you will be withdrawn from participation in this study. If you are unable to participate in the focus group study due to healthcare or other emergencies, you will be removed from the focus group interview and treated by Camp Possibilities staff.

The information that you give in the study will be anonymous. Your name will not be collected or linked to your answers. Some basic background information such as age and gender will be included in the results of this research study and may be reported in publications, journals or at scientific meetings. Your name will not be used in any report.

The information that you provide in the study will be handled confidentially. However, there may be circumstances where this information must be released or shared as required by law. The University of Arizona Institutional Review Board may review the research records for monitoring purposes.

Further information regarding this study, or if you have any questions, concerns, or complaints about the study you may contact Rita Meadows, (Principal Investigator) at rmeadowsaprn@email.arizona.edu or Dr. Marylyn McEwen, Dissertation Chair, at marylynm@email.arizona.edu.

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact the Human Subjects Protection Program at 520-626-6721 or online at http://rgw.arizona.edu/compliance/human-subjects-protection-program.

Signing the consent form

I have read (or someone has read to me) this form, and I am aware that I am being asked to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I voluntarily agree to participate in this study.

I am not giving up any legal rights by signing this form. I will be given a copy of this form.

Printed name of subject	Signature of subject	Date

APPENDIX B:

PARENTAL PERMISSION FOR ADOLESCENTS TO PARTICIPATE IN RESEARCH FORM

University of Arizona
Parental Permission for Adolescent to Participate in Research

Study Title: Facilitators and Inhibitors of Independent Self-Management of Adolescents with Type 1 Diabetes

Principal Investigator: Rita Elizabeth Jean Meadows, MSN, FNP-BC

You are being asked to allow your child to participate in a research study. Your child's participation in this research study is voluntary and he/she does not have to participate. This document contains important information about this study and what to expect if you decide to allow your child and to participate. Please consider the information carefully. Feel free to ask questions before making your decision whether or not to allow your child to participate.

The purpose of this research study is to find out:

1. What your child thinks are the Type 1 diabetes self-management behaviors? and
2. What are the things that might help or get in the way of your child's success in independently managing his/her Type 1 diabetes?

Your child is being asked to participate in a focus group interview that will take 60 minutes to complete and complete a demographic data form that will take approximately 5-minutes. Your child may stop his/her participation in this study at any time. There are no expected physical risks to your child as a result of participating in this study. However, loss of confidentiality is a potential risk. Even though we will tell all participants in the study that the comments made during the focus group should be kept confidential, it is possible that participants may repeat comments outside the group. Although no injury directly related to the research is foreseeable, if your child suffers any disease-related events such as hyper- and hypoglycemic events, or adverse behavioral, emotional or mental health events during the focus group interview, your child will be provided time and healthcare resources necessary to manage the event by the Camp Possibilities healthcare staff and/or Camp Possibilities behavior support team. Your child will not be paid for participation in this study. Your child will not benefit directly from participating in this study. However, this study will contribute to current body of knowledge and may inform development of transition programs for adolescents transitioning to independent self-management.

Permission/assent forms, audio recordings, demographic forms, handwritten field notes, memos, and transcripts- a written version of the audio recordings of the focus group interviews will be uploaded, safely stored and managed in an encrypted password-protected computer during camp. The data will then be uploaded into a software system that will help analyze the data. A professional, secure and confidential transcription service based in the United States will be used to create the written transcripts from the audio recordings. All permission/assent forms will be stored in a in a locked box in the PI's private quarters during camp and until

transferred to storage at the University of Arizona College of Nursing. All audio recordings will be stored on a password protected encrypted computer and will be destroyed once they are transcribed. Transcription files will be digitally saved on a password protected encrypted computer. Any data that reveals the name of your child will be removed from all transcripts and forms. Fictional names may be used to match transcripts to demographic questionnaires. Data will be kept for six years after your child turns 18 years old. Only the Principle Investigator (PI) and the PI's dissertation committee will have access to the data. Information collected will not be used or shared for future research studies.

Data is collected during the focus group only. Your child may take breaks or stop the interview at any time and may withdraw from the study at any time without any ill will; and your child may continue to participate in the Camp if he/she withdraws from the study. Focus group interviews will be conducted in a private, vacated living room area in the healthcare staff's living quarters. Interviews will be conducted before camp orientation to minimize disruption of camp activities. Upon completion of the focus group, your child will return to Camp activities.

If your child is withdrawn from the focus group due to disruptive behavior or illness, your child will be counted as an enrolled participant and the data that is collected up until point of withdrawal may still be used. If your child is withdrawn from Camp Possibilities attendance before the focus group interviews begin, your child will be withdrawn from participation in this study. If your child is unable to participate in the focus group study due to healthcare or other emergencies, your child will be removed from the focus group interview and treated by Camp Possibilities staff.

The information that your child gives in the study will be anonymous. Your child's name will not be collected or linked to your child's answers. Some basic background information such as age and gender will be included in the results of this research study and may be reported in publications, journals or at scientific meetings. Your child's name will not be used in any report.

The information that your child provides in the study will be handled confidentially. However, there may be circumstances where this information must be released or shared as required by law. The University of Arizona Institutional Review Board may review the research records for monitoring purposes.

For questions about your child's rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact the Human Subjects Protection Program at 520-626-6721 or online at http://rgw.arizona.edu/compliance/human-subjects-protection-program.

Signing the consent form

I have read (or someone has read to me) this form, and I am aware that I am being asked to give permission for my child to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I voluntarily agree to allowing my child to participate in this study.

I am not giving up any legal rights by signing this form. I will be given a copy of this form.

Printed name of subject	Signature of subject	Date

HSPP Use Only:
Consent Script non-federal v2019-02

APPENDIX C:

DEMOGRAPHIC INFORMATION SHEET

Facilitators and Inhibitors of Independent Self-Management of Adolescents with Type 1 Diabetes

Demographic Information Form

Instructions: Please provide a response for each of the following questions:

1. What is your age? _____

2. What is you sex? Female ○ Male ○ Non-binary ○

3. With which racial or ethnic category do you identify?

African American ○ Asian/Pacific Islander ○ Caucasian ○ Latino ○

Other: _____

4. What grade will you be entering in the fall? _____

5. How long have you been diagnosed with Type 1 Diabetes? ____ years ____ months

6. Have you ever discussed transitioning from pediatric to adult healthcare with your healthcare provider? Yes ○ No ○

7. At what age do you plan on transitioning from pediatric to adult healthcare?
_____ years old

9. Have you ever discussed any of the following topics with your parent/guardian or healthcare provider?

Nutrition	Yes ○	No ○	
Physical activity and exercise		Yes ○	No ○
Future career or vocation counseling		Yes ○	No ○

APPENDIX D:

THE UNIVERSITY OF ARIZONA INSTITUTIONAL REVIEW BOARD APPROVAL LETTER

THE UNIVERSITY OF ARIZONA
Research, Discovery & Innovation

Human Subjects Protection Program

1618 E. Helen St.
P.O Box 245137
Tucson, AZ 85724-5137
Tel: (520) 626-6721
http://rgw.arizona.edu/compliance/home

Date:	June 05, 2019
Principal Investigator:	Rita Elizabeth Meadows
Protocol Number:	1905648707
Protocol Title:	Facilitators and Inhibitors of Independent Self-Management of Adolescents with Type 1 Diabetes
Determination:	Approved
Expiration Date:	June 03, 2024

Documents Reviewed Concurrently:

Data Collection Tools: *Meadows_Dissertation_IRB_Demographic Data Form.docx*
Data Collection Tools: *Meadows_Research Interview Questions.docx*
HSPP Forms/Correspondence: *Advisor Confirmation Email.pdf*
HSPP Forms/Correspondence: *Confirmation for Scientific Review and Department Review.pdf*
HSPP Forms/Correspondence: *IRB application_Meadows.pdf*
HSPP Forms/Correspondence: *Meadows_list_of_research_project_personnel_2-3_v2018.pdf*
HSPP Forms/Correspondence: *Meadows_Vulnerable_populations_application.pdf*
Informed Consent/PHI Forms: *Meadows_Assent Form_.docx*
Informed Consent/PHI Forms: *Meadows_Assent Form_.pdf*
Informed Consent/PHI Forms: *Meadows_Parent Permission Form.docx*
Informed Consent/PHI Forms: *Meadows_Parent Permission Form.pdf*
Other: *COI Certification Complete for 1905648707.msg*
Other Approvals and Authorizations: *Meadows_CampPossibilities_external_site approval.pdf*
Recruitment Material: *Meadows_IRB_RECRUITMENT FLYER (1).docx*

Regulatory Determinations/Comments:

- The project is not federally funded or supported and has been deemed to be no more than minimal risk.
- The project listed is required to update the HSPP on the status of the research in 5 years. A reminder notice will be sent 60 days prior to the expiration noted to submit a 'Project Update' form.

This project has been reviewed and approved by an IRB Chair or designee.

- The University of Arizona maintains a Federalwide Assurance with the Office for Human Research Protections (FWA #00004218).
- All research procedures should be conducted according to the approved protocol and the policies and guidance of the IRB.
- The Principal Investigator should notify the IRB immediately of any proposed changes that affect the protocol and report any unanticipated problems involving risks to participants or others. Please refer to Guidance Investigators Responsibility after IRB Approval, Reporting Local Information and Minimal Risk or Exempt Research.

- All documents referenced in this submission have been reviewed and approved. Documents are filed with the HSPP Office.

APPENDIX E:

RECRUITMENT FLYER

INVITATION TO CAMPERS and Guardians:

HELP US UNDERSTAND INDEPENDENT SELF-MANAGEMENT OF TYPE 1 DIABETES

You are being invited to participate in a research study because you have Type 1 Diabetes, you are 15-17 years of age, and you are attending Camp Possibilities.

The purpose of the study, **the facilitators and inhibitors of independent self-management of the adolescent with Type 1 Diabetes**, is to learn from the adolescents about transitioning from dependent to independent diabetes self-management.

What you are being asked to do if you participate in the study:

- Participate in a 1-hour focus group interview, one for boys and the other for girls.
    - Questions will focus on:
        - What are the Type 1 diabetes self-management behaviors?
        - What are the things that might help or get in the way of your being successful in independently managing your Type 1 diabetes?

What you should know:

- IF you are interested in participating in the study more information will be provided at Camp Orientation.
- IF you agree to participate in the study, both you and your guardian will sign a consent form - after the study is explained to you – at Camp Orientation.
- There are no expected risks to you as a result of participating in this study and you may stop participating at any time during the focus group.
- You will not be paid for participating in this study.
- The research study is being conducted by Rita Meadows, MSN, FNP-BC, who is a graduate student at the University of Arizona, College of Nursing.

Why this study is important:

The outcomes from this study will help us to develop a future Transition Program, at Camp Possibilities and, with future programs for adolescents who are transitioning from pediatric to adult health care.

For further information regarding this study contact Rita Meadows, (Principal Investigator) at 302-519-8264 or rmeadowsaprn@email.arizona.edu or Dr. Marylyn McEwen, Dissertation Chair, the University of Arizona marylynm@email.arizona.edu.

An Institutional Review Board responsible for human subjects research at The University of Arizona reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

APPENDIX F:

APPROVAL FROM CAMP DIRECTOR TO CONDUCT STUDY

Camp Possibilities
PO Box 4111
Wilmington, De 19807

May 5, 2019

University of Arizona Institutional Review Board
c/o Office of Human Subjects
1618 E Helen St
Tucson, AZ 85721

Please note that **Ms. Rita Meadows**, UA Graduate Student, has permission of Camp Possibilities to conduct research at Camp Possibilities, held at Camp Ramblewood 2564 Silver Lane Darlington, Maryland, for her study, **"Facilitators and Inhibitors of Independent Self-Management of Adolescents with Type 1 Diabetes"**.

A recruitment flyer that invites adolescents with T1DM to participate in the study will be sent to the residence of adolescents and their guardian(s) who have been accepted into the 2019 Camp Possibilities. The recruitment flyer, with Ms, Meadows' contact information (cell phone), will be sent via U.S. mail one month before the summer camp begins. The recruitment flyer will include the purpose of the research study, what will be asked of the adolescent if they participate in the study, and the length of time required to participate in the one-time focus group. The recruitment flyer will also be provided by Ms, Meadows to the adolescent/guardian dyad on the first day at camp during sign-in. Ms, Meadows will ask each of the adolescent/guardian dyads if they are interested in learning more about the study and if so, Ms. Meadows will meet with them as soon as they are signed in to camp. Campers that suffer disease-related events such as hyper- and hypoglycemic events during the focus group interview will be provided time and healthcare resources necessary to manage the event by the Camp Possibilities staff. Ms. Meadows' on-site research activities will be completed by August 2, 2019.

Camp Possibilities will receive no direct benefit of this study. Ms. Meadows has agreed to provide to my office a copy of the University of Arizona IRB-approved consent document before she recruits participants on campus.

If there are any questions, please contact my office.

Signed,

Jeff Dietz, Camp Director

APPENDIX G:

FOCUS GROUP INTERVIEW GUIDE

Facilitators and Inhibitors of Independent Self-Management of Adolescents with T1DM Interview Guide (page one)

Research Question 1: What are the self-management behavior skills required for the adolescent with T1DM during transition from dependent to independent T1DM self-management?

1. Tell me about what you think the self-management or behavioral skills are that you will need to do when you are taking care of your T1DM by yourself.
2. Think of a time when you had to compensate for increased physical activity, tell me what you did.
    a. What do you do to help you to remember to perform the behaviors of self-management?
3. Who are the healthcare providers that help you learn the skills needed to manage your BG levels?
    a. What do you think will be the difference between adult and pediatric care as you assume responsibility or independent management of your T1DM?

Research Question 2: What facilitates everyday participation in self-management behaviors for adolescents with T1DM?

1. There are a lot of people that can help you to remember to self-manage your T1DM, and help you get the things you need to manage your T1DM. Who helps you manage your blood glucose levels and symptoms of hyper- and hypoglycemia?
    a. What are the most helpful behaviors that people do to help you manage your BG levels?
    b. Are there any behaviors that people are not doing that you think may help you better manage your BG levels?
2. During your last visit to your healthcare providers, what did they do that made you feel like they were helping you with your everyday self-management of your T1DM?
    a. Are there any behaviors that your healthcare providers are not doing that you think may help you better manage your BG levels?
3. Sometimes people do not understand what they can do to help you self-manage your BG levels. Think of a time when you have encouraged or taught someone about diabetes self-management.
    a. What parts of self-management did you teach or encourage that person to do that would help you to manage your T1DM?

Research Question 3: What are the barriers to participating in everyday self-management behaviors for adolescents with T1DM?

1. Think of a time when someone did something that made it harder for you to manage your BG levels.
    a. What did they do to make it harder for you to manage your BG levels?
    b. Have you ever been bullied or cast out from a group because of having T1DM?
    c. How did you respond to these behaviors?
2. During your last few visits to any of your healthcare providers, what did they do or say that make you feel like it would be hard for you to manage your BG levels every day?
    a. How do you respond to these behaviors?

Facilitators and Inhibitors of Independent Self-Management of Adolescents with T1DM Interview Guide (page two)

1. Do you think that you are able to change any of the behaviors of people that make it harder for you to manage your BG levels?
    a. What behaviors do you think that you can't change?
    b. What behaviors do you think that you can change?
2. Over the past few weeks, what are some of the things that you have done yourself, that have made it harder for you to manage your T1DM?
        a. What behaviors do you think that you can change?

What behaviors do you think that you can't change?

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